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ABSTRACT

This report reviews federal laws and programs affecting persons with disabilities and assesses the extent to which they: provide incentives or disincentives to the establishment of community-based services for handicapped individuals; promote the full integration of such individuals in the community, in schools, and in the workplace; and contribute to the independence and dignity of such individuals. An introductory chapter provides a description of the demographics of the U.S. disabled population. A list of federal programs serving people with disabilities is prioritized according to federal expenditures, with an estimated number of persons with disabilities served. Summarized are the National Council on the Handicapped's legislative recommendations in 10 issue areas: equal opportunity laws; employment; disincentives to work under social security laws; prevention of disabilities; transportation; housing; community-based services for independent living; educating children with disabilities; personal assistance such as attendant services, readers, and interpreters; and coordination. The recommendations propose modifications in the expenditure of disability-related dollars to improve the ability of persons with disabilities to live with dignity and as independently as possible within their communities. The report concludes with biographies of Council members. (JDD)

ED301009

A Report to the President and to the Congress of the United States

TOWARD INDEPENDENCE

An Assessment of Federal Laws and Programs Affecting Persons With Disabilities — With Legislative Recommendations

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EC 211 758

February 1986

National Council on the Handicapped

A Report to the President and to the Congress of the United States

TOWARD

INDEPENDENCE

An Assessment of Federal Laws and Programs Affecting Persons With Disabilities — With Legislative Recommendations

February 1986

National Council on the Handicapped

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Acknowledgment

The Council wishes to acknowledge and convey its sincere appreciation to the many individuals and organizations who contributed to this report. Numerous people with disabilities, parents, service providers, advocates, business persons, legislative policy advisors, and other experts from all the fifty states contributed to this effort by participating in public forums, attending advisory meetings, and otherwise providing input and assistance to the Council in the process of developing the ideas and recommendations contained in the report.

TOWARD INDEPENDENCE:
AN ASSESSMENT OF FEDERAL LAWS AND PROGRAMS
AFFECTING PERSONS WITH DISABILITIES —
WITH LEGISLATIVE RECOMMENDATIONS

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Detailed topic papers discussing the recommendations presented in this report have been published in a separate Appendix. The Government Printing Office Stock Number for the Appendix is: 052-003-01023-2.

The views contained in this report do not necessarily represent those of the Administration, as this document has not been subject to the A-19 Executive Branch review process.

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An Independent
Federal Agency

LETTER OF TRANSMITTAL

(Text of identical letters sent to the President of the United States, the President of the Senate, and the Speaker of the House of Representatives)

February 1, 1986

The National Council on the Handicapped is pleased to issue this report on Federal laws and programs serving people with disabilities. It was developed in response to a specific statutory mandate that the Council:

> assess the extent to which [Federal] programs provide incentives or disincentives to the establishment of community-based services for handicapped individuals, promote the full integration of such individuals in the community, in schools, and in the workplace, and contribute to the independence and dignity of such individuals. . . [and] recommend to the President and Congress legislative proposals for increasing incentives and eliminating disincentives in Federal programs based on the assessment made. . .
> (Public Law No. 98-221, Section 401a)

The Council developed this report in consultation with knowledgeable persons with disabilities and experts on disability service programs throughout the country.

The report summarizes the Council's findings and presents its recommendations, reflecting the consensus of the Council on the issues addressed. As requested by Congress in the statutory directive concerning the report, it includes a listing of Federal programs serving people with disabilities prioritized according to Federal expenditures. The recommendations presented in the report are designed to improve the ability of persons with disabilities to live with dignity and as independently as possible within their communities. An Appendix under separate cover presents ten topic papers providing the Council's detailed analysis and conclusions upon which the recommendations in this report are based. The ten topic areas were selected by the Council for in-depth analysis and study because of their clear importance to persons with disabilities and to Federal policy regarding disability programs. The Council's recommendations offer the most constructive and realistic solutions it has identified to problems in each of these topic areas. The Council recognizes that there may be some disagreement about what are the "best" solutions in specific cases, but it is confident that everyone involved in disability issues will agree that the issue areas examined in this report are areas that must be addressed if we hope to achieve a coherent and constructive Federal approach to disability.

In analyzing Federal programs that affect people with disabilities and in formulating legislative recommendations, the Council has been very cognizant of the financial implications of its proposals, and has consistently sought to develop practical, fiscally responsible approaches. Indeed, one of the Council's key objectives has been to suggest ways in which Federal expenditures related to disability can be more prudently spent, and ineffectiveness and counterproductivity minimized. The Council is confident that if the recommendations in this report are implemented, current Federal expenditures for disability can be significantly redirected from dependency-related approaches to programs that enhance independence and productivity of people with disabilities, thereby engendering future efficiencies in Federal spending.

The Council by no means views the submission of the recommendations presented in this report as completing its responsibilities in regard to the issues addressed. The report represents, rather, an agenda for the Council's work in the future, in conjunction with other statutory duties assigned to it. The Council will continue to monitor Federal programs serving people with disabilities, and to advise the Administration and Congress of its findings. The Council will continue to analyze the issues discussed herein, as well as to examine other topics not covered in this report. The Council expects to increase its coordinative role in the Federal policy arena by actively pursuing and encouraging communication linkages among consumers with disabilities and their families and Federal, State and local policy makers, program administrators, and service providers. The Council will also continue to attend to a major statutory responsibility of setting general policies for and monitoring the operation of the National Institute of Handicapped Research, one of our Nation's principal resources for investigating and testing solutions to problems related to disability.

The Council values the opportunity presented by this report to make a contribution to disability policy, and hopes that it marks a step toward a more active and productive dialogue among all the people who influence and are affected by disability policy.

Sincerely,

Sandra Parrino

Sandra S. Parrino
Chairperson

Description of the National Council on the Handicapped

The National Council on the Handicapped is an independent Federal agency comprised of 15 members appointed by the President of the United States and confirmed by the Senate. Established by the 95th Congress in Title IV of the Rehabilitation Act of 1973 (as amended by Public Law No. 95-602 in 1978), the Council was initially an advisory board within the Department of Education. In 1984, however, the Council was transformed into an independent agency by the Rehabilitation Act Amendments of 1984 (Public Law No. 98-221).

The Council is charged with reviewing all laws, programs, and policies of the Federal Government affecting disabled individuals and making such recommendations as it deems necessary to the President, the Congress, the Secretary of the Department of Education, the Commissioner of the Rehabilitation Services Administration, and the Director of the National Institute of Handicapped Research (NIHR). The Council is given explicit authority to establish general policies for and monitor the performance of NIHR, and to review and approve standards concerning Independent Living and Projects With Industry programs. In addition, the Council has been statutorily directed to submit to the President and the Congress, by February of 1986, the present report analyzing Federal programs and presenting legislative recommendations to enhance the productivity and quality of life of Americans with disabilities.

Whereas many government agencies deal with issues and programs affecting people with disabilities, the National Council on the Handicapped is the only Federal agency with the mandated responsibility to address, analyze, and make recommendations on issues of public policy which affect people with disabilities regardless of age, disability type, perceived employment potential, perceived economic need, specific functional ability, status as a veteran, or other individual circumstances. The Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring a coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

The National Council on the Handicapped

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Executive Summary

The National Council on the Handicapped is charged by statute with reviewing Federal laws and programs affecting persons with disabilities and assessing the extent to which they "provide incentives or disincentives to the establishment of community-based services for handicapped individuals, promote the full integration of such individuals in the community, in schools, and in the workplace, and contribute to the independence and dignity of such individuals."

In this report, the Council presents its findings, conclusions, and legislative recommendations based upon its review and assessment of Federal laws and programs. The report includes a list of major Federal programs serving individuals with disabilities, ranked according to expenditures, with an estimated number of persons with disabilities served. From its analysis of such information, the Council draws three general conclusions:

1. ***Approximately two-thirds of working-age persons with disabilities do not receive Social Security or other public assistance income.***
2. ***Federal disability programs reflect an overemphasis on income support and an underemphasis of initiatives for equal opportunity, independence, prevention, and self-sufficiency.***
3. ***More emphasis should be given to Federal programs encouraging and assisting private sector efforts to promote opportunities and independence for individuals with disabilities.***

Our nation's current annual Federal expenditure on disability benefits and programs exceeds $60 billion. This report proposes some fiscally responsible approaches for spending disability-related dollars more prudently and productively. The Council is strongly convinced that present and future costs of disability to the Nation are directly related to the degree of success we attain in reducing existing barriers, both structural and attitudinal, and in providing appropriate services to individuals with disabilities so that they may realize their full potential and become more independent and self-sufficient.

The Council has focused in detail upon ten major topic areas of particular importance to individuals with disabilities. These topics are discussed extensively in individual topic papers presented in the separate Appendix to this report. The Council's legislative recommendations in regard to the ten issue areas are summarized in the body of the report. They include the following:

Equal Opportunity Laws: The Council recommends the enactment of a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.

Employment: To increase employment among people with disabilities—a drastically underemployed segment of the population—the Council recommends several legislative changes, concerning the transition from school to work, supported employment, private sector initiatives, job training, job development, and placement.

Disincentives To Work Under Social Security Laws: The Council outlines several ways in which provisions of existing Social Security laws—Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare—serve to discourage and penalize people with disabilities if they seek to become employed and self-supporting. In response to these work disincentives, the Council recommends corrective amendments to the problematic provisions.

Prevention of Disabilities: To promote the prevention of disabilities and to assure that individuals having disabilities do not suffer unnecessary secondary disabilities or exacerbation of their impairments, the Council recommends that the Federal Government mount a national program for the prevention of disabilities.

Transportation: The Council recommends amendments to Federal transportation legislation to achieve the Nation's established policy that "disabled people have the same right to use public transportation as non-disabled persons." Proposals relate to urban mass transit, air transportation, intercity and interstate buses, and private vehicles.

Housing: To permit people with disabilities an opportunity to obtain appropriate housing, which is an important prerequisite to obtaining employment, living independently, and avoiding costly institutionalization, the Council makes several recommendations designed to prohibit housing discrimination and to promote increased appropriate and accessible housing for persons with disabilities.

Community-Based Services for Independent Living: To achieve productivity and independence, people with disabilities require a range of support services according to the nature and degree of their disabilities. The Council proposes a variety of measures, including amendments and funding support under Parts A and B of Title VII of the Rehabilitation Act, to promote the availability of community-based services for independent living.

Educating Children With Disabilities: The Council makes legislative recommendations regarding educational opportunities for children with disabilities. These recommendations respond to: the need for special education and related services during infancy; the need to educate children with special needs in regular education facilities; and the need to assess progress made since the enactment of the Education for All Handicapped Children Act.

Personal Assistance: Attendant Services, Readers, and Interpreters: Because of the critical importance of such services in fostering independence and avoiding expensive institutionalization, the Council recommends a national commitment to developing a quality system of attendant services, readers, and interpreters.

Coordination: The Council recommends that all Federal and Federally supported disability-related programs be authorized and required to develop a joint plan for the systematic coordination of services and benefits.

Introduction

Our country calls not for the life of ease, but for the life of strenuous endeavor.
President Theodore Roosevelt, 1899

As for other Americans, life for people with disabilities involves striving, working, taking risks, failing, learning, and overcoming obstacles. We have all had the experience of seeking something that eludes us, of trying to reach a goal that seems to dance just out of reach. Most of us have also had the rewarding experience of surmounting obstacles to achieve a goal or accomplish a task, succeeding even though someone else or even we ourselves doubted we could do it.

A major difference between persons with disabilities and other individuals is the number, degree, and complexity of the barriers they face in trying to achieve their personal goals and fulfillment. Some of these barriers result from the disabilities themselves—a disability may be considered to be the lack of some mental, physical, or emotional "tool" which most other people can call upon in addressing life's tasks. A person with a physical disability, for example, may be unable to perform certain physical movements or functions that other people take for granted. A person with a sensory disability may lack or have significant impairment of one of the major senses, such as sight or hearing, which for other people provide important channels for receiving information about the world around them. An individual with a mental or emotional impairment may have a reduced ability to deal with the stresses of life or to sort out the real from the imagined. And people with cognitive impairments, such as learning disabilities and mental retardation, have disorders in the ability or rate of accepting, processing, storing, and recalling information.

But whatever the limitations associated with particular disabilities, people with disabilities have been saying for years that their major obstacles are not inherent in their disabilities, but arise from barriers that have been imposed externally and unnecessarily. As an international group of experts concluded:

> *Despite everything we can do, or hope to do, to assist each physically or mentally disabled person achieve his or her maximum potential in life, our efforts will not succeed until we have found the way to remove the obstacles to this goal directed by human society—**the physical barriers** we have created in public buildings, housing, transportation, houses of worship, centers of social life, and other community facilities—**the social barriers** we have evolved and accepted against those who vary more than a certain degree from what we have been conditioned to regard as normal. More people are forced into limited lives and made to suffer by these man-made obstacles than by any specific physical or mental disability.*
> *Report of the United Nations Expert Group Meeting on Barrier-Free Design, **International Rehabilitation Review**, vol. 26, p. 3 (1975).*

As detailed subsequently in this report, our Nation's current annual Federal expenditure on disability benefits and programs is more than $60 billion. Overall Federal spending associated with disability can be expected to mushroom as the "baby boom" generation grows older and age-related disabilities increase. The present and future costs of disability to our nation are directly related to the degree of success we attain in reducing existing barriers, both structural and attitudinal, and in providing appropriate services to individuals with disabilities so that they may realize their full potential and become more independent and self-sufficient. If we are unsuccessful, dependency will increase and be accompanied by increasing costs for services and care as they become more custodial in nature.

The time is ripe for a careful assessment of disability-related expenditures and programs to see how effective they are in enhancing independence and equality of opportunity for people with disabilities. To this end, Congress has directed the National Council on the Handicapped to assess the extent to which Federal programs serving people with disabilities:

> *provide incentives or disincentives to the establishment of community-based services for handicapped individuals, promote the full integration of such individuals in the community, in schools, and in the workplace, and contribute to the independence and dignity of such individuals.*
> *(Section 401 of the Rehabilitation Act of 1973, as amended)*

In response to this mandate, the Council has engaged in a variety of efforts to collect pertinent information and viewpoints. It has:

- Examined current legislation and programs,
- Collected and analyzed information about exemplary programs,
- Reviewed existing analyses of Federal programs and disability issues,
- Consulted with experts on programs for persons with disabilities and consumers of disability services,
- Conducted special seminars and hearings, and
- Conducted forums with persons with disabilities and their families throughout the country.

Based upon such information, the Council selected ten topic areas of critical importance for in-depth analysis and recommendations. The resulting topic papers are presented in a separate appendix to this report. The major conclusions of the detailed topic papers, along with an overview of the population with disabilities and a listing and summary review of Federal programs providing services to individuals with disabilities, are presented in the body of this report.

The Population With Disabilities

The social category of people with disabilities encompasses a wide diversity of individuals. It includes the neighbor who has just had heart by-pass surgery, the boy down the street with cerebral palsy, the business executive who has been hospitalized for severe depression, the blind woman who works in the office downstairs, the mentally retarded landscaper at the local plant nursery, and last year's champion diver at the local high school who now uses a wheelchair because of a spinal cord injury.

Various estimates place the number of Americans with disabilities between 20 million and 50 million persons, with a figure of 35 or 36 million being the most commonly quoted estimate. A precise and reliable overall figure is not currently available, due to differing operational definitions of disability, divergent sources of data, and inconsistent survey methodologies, which together make it impossible to aggregate much of the data that are available.

Most existing studies of the disabled population employ one of two major approaches, each of which has its own shortcomings and limitations. The ***health conditions*** approach looks at all conditions or limitations which impair the health or interfere with the normal functional abilities of an individual. This approach usually tends to produce very large numbers of "disabilities," because of the inclusion of individuals with health problems that would not normally result in their classification as disabled or handicapped. For example, the Health Interview Survey conducted by the National Center for Health Statistics has estimated that there are over 160 million impairments and chronic conditions in the civilian non-institutionalized population of the U.S. (Mathematica Policy Research, 1984, p. 3). These figures include large numbers of various types of circulatory conditions, respiratory conditions, digestive conditions, and skin and musculoskeletal conditions, not typically categorized as disabilities. Because of its focus on the medically oriented notions of health, the health conditions approach also does not provide adequate data on such conditions as learning disabilities and mental conditions.

The other major approach to disability data—the ***work disability*** approach—is also problematic. Such studies focus on individuals' reports that they have a condition that prevents them from working or limits their ability to work. The 1980 Census of Population, for example, contains a count of the number of persons age 16 or above who report the presence of a physical, mental, or other health condition which has lasted for six or more months that limits the kind or amount of work that they can accomplish at a job. Of the total 170 million people ages 16 and above who were counted in 1980, 22.7 million (or 13.3 percent) reported

having work disabilities. Furthermore, two-thirds of these individuals (or 15.1 million persons) report that their disability actually prevents them from working.

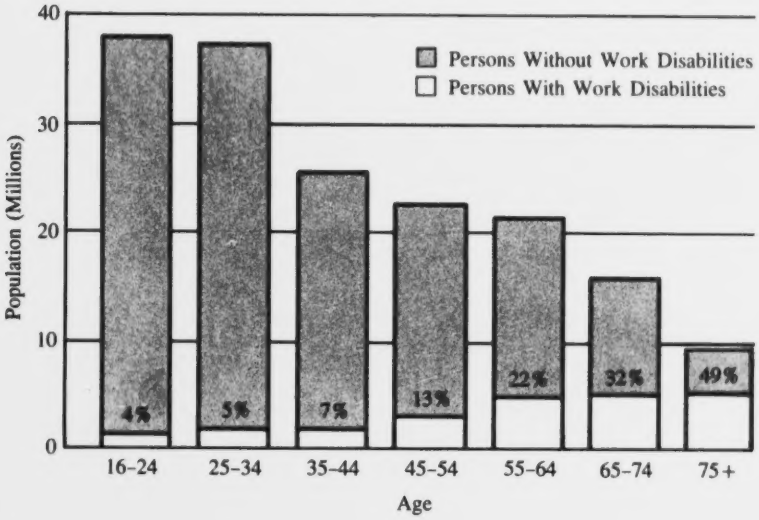
Such work disability figures probably provide a reasonably accurate gross estimate of the numbers of people of working age with disabilities. Such studies have their own shortcomings, however. They underestimate the numbers of people at lower age ranges—the 16 to 24 age group, for example—some of whom are not ready to join the work force and for whom the self-identification as either work disabled or not is often not meaningful. They also skew the population counted. Persons who are out-of-work or who are not seeking work have psychological motives for reporting themselves as having a work disability, whether or not they truly have a disability. Independent disabled persons with a strong work history and who are currently employed, on the other hand, will often refuse to categorize themselves as having a work disability, even if they have a significant disabling condition such as blindness, paralysis, or absence of a limb. For these reasons, work disability studies tend to underestimate the total numbers of people with disabilities, and to overestimate the unemployment and nonparticipation in the labor force rates of people with disabilities.

The Council has been urging the Bureau of the Census to incorporate into the 1990 Census some questions concerning the numbers of persons with various types of physical and mental impairments in the U.S., so that a more accurate profile of the population with disabilities can be obtained, thus providing a more reliable data base for Federal policy, planning, and service delivery. The Council will issue in the near future a monograph summarizing information from currently available sources and discussing the needs for additional disability data. For the purposes of the present report, the remainder of this section summarizes some pertinent statistical facts gleaned from existing studies that, in spite of the limitations previously noted, do provide a rough profile of the population of Americans with disabilities.

Correlation of Disability and Age

The incidence of disability increases dramatically with age. According to 1980 Census figures, 3.6 percent of all individuals ages 16–24 and 5.1 percent of the 25–34 age group report a work disability. These figures are quite low when compared to those for older age categories; 22.5 percent of all individuals ages 55–64, 32.2 percent of the 65–74 age group, and 48.5 percent of the 75+ age group report a work disability. Youths between the ages of 16 and 24 account for 1.4 million (or only 6 percent) of the total number who report work disabilities, while 4.8 million persons between the ages of 55 and 64 report disabilities, or 21.3 percent of the total. Nearly two-thirds of all persons who report work disabilities are in the age range of 55 and above. The strong correlation of disabilities with advancing age is illustrated in Chart 1.

Chart 1: Adult Population by Age in 1980



The Working Age Population With Disabilities

According to 1980 Census figures, some 12.9 million people between the ages of 16 and 64 reported a work disability. 4.2 million (or 32.2 percent) of the persons reporting a work disability were employed in the labor market at the time the Census was taken. The number of unemployed persons with a work disability amounted to 0.6 million. Almost 63 percent of the total number reporting disabilities were not in the labor force (i.e., neither employed nor seeking employment) at the time of the Census. Nearly one in five of all people not in the labor force report a work disability (19.1 percent), while only 4.4 percent of all who are employed report a work disability.

Census figures also indicate some correlation between work disability and poverty. Of the 12.9 million persons of working age reporting the presence of a work disability, 2.6 million (or 20.1 percent) have family incomes that are below the Federal poverty threshold. This is more than double the 9.1 percent rate of the general population which has a family income below the poverty line. People reporting work disabilities have a higher representation in the lower family income categories. Of all individuals below the poverty line, 17.7 percent claim to have a work disability. In contrast, only 6.4 percent of individuals with family incomes above twice the poverty line report a work disability. On the other hand, in spite of the overrepresentation of people who report work disabilities in the poverty category, nearly four out of five disabled individuals have family incomes that are above the poverty threshold.

Types of Disability

According to National Center for Health Statistics figures, in the civilian noninstitutionalized population of the U.S., there are 18.4 million people with orthopedic impairments or deformities; 17 million persons with hearing impairments; 8.2 million with visual impairments; 2.1 million with speech impairments; 26.8 million with arthritis; 24.3 million with hypertensive disease; 16.4 million with heart disease; 1.6 million missing extremities or parts of extremities; and 1.2 million who are partially or completely paralyzed (Mathematica Policy Research, 1984, p. 2). Another study found that there are approximately 5.7 million mentally retarded persons in the U.S., 2.4 million persons with epilepsy, 950,000 who have cerebral palsy, and about 95,000 with autism (EMC Institute, 1979).

Estimates are that some 3 million Americans have been diagnosed as having a severe mental disorder, with the number of individuals with chronic mental illness placed at between 1.7 million and 2.4 million, including 900,000 who are institutionalized (Goldman, Gattozzi, and Taub, 1981). The National Institute of Mental Health estimates, however, that fewer than 20 percent of Americans suffering from any mental disorder seek mental health services from mental health specialists or general physicians (NIMH, "Mental Health, United States 1985").

Nearly 6.5 million noninstitutionalized persons use one or more special aids in order to get around; these include: 645,000 people who use wheelchairs; 689,000 who use a walker; 613,000 who use crutches; 205,000 with an artificial leg or foot; 66,000 with an artificial arm or hand; 2,714,000 who use a cane or walking stick; 1,492,000 who wear special shoes; 398,000 who wear a leg or foot brace; and 1,004,000 who wear some other type of brace (Mathematica Policy Research, 1984, p. 41).

Statistics from the Office of Special Education and Rehabilitative Services, U.S. Department of Education, indicate that the numbers of "handicapped children" served under Federally assisted education programs in the 1981–1982 school year were as follows: children with specific learning disabilities—1,624,989; children with speech impairments—1,136,309; mentally retarded—786,775; seriously emotionally disturbed—339,629; orthopedically impaired—57,967; deaf or hard of hearing—74,694; visually handicapped—29,174; deaf and blind—2,486; multiply handicapped (including those with severe and profound mental retardation)—71,289; and children with other health impairments—79,519 (Mathematica Policy Research, 1984, p. 101).

An Assessment of Federal Laws and Programs Affecting Persons With Disabilities

Complexities, inconsistencies, and fragmentation in the various Federal laws and programs that affect Americans with disabilities might suggest that the United States has no coherent Federal policy on disability. Echoing a chorus of previous commentators, President Reagan has described "the patchwork quilt of existing policies and programs," and has decried the fact that within the Federal "maze," programs often overlap or work at cross-purposes (President Reagan, Remarks on Signing Proclamation 5131, Establishing the National Decade of Disabled Persons, Nov. 28, 1983). Programmatic inadequacies and inconsistencies do not mean, however, that there has been no clear national goal regarding citizens with disabilities. With surprising consistency, the branches of American Government, disabled individuals and their families, and service and consumer agencies have agreed that the overall goal of the nation in regard to persons with disabilities is to insure the rights of such individuals to equality of opportunity and to independence.

Confusion and inconsistency have resulted, not from lack of consensus about the goal, but from the historical and continuing failure to structure and administer some Federal laws and programs in such a way as to reflect and further the national goal. The nation's goal regarding citizens with disabilities may be clear and meritorious, but Federal programs and laws that should serve as paths toward this goal have often deviated or even retreated from it. A major purpose of this report is to suggest ways in which various Federal laws and programs can be redirected towards the national goal of assuring equal opportunities and promoting independence for Americans with disabilities.

Toward Independence And Equality For Citizens With Disabilities

We hold these truths to be sacred and undeniable: that all men are created equal and independent, that from that equal creation they derive rights inherent and inalienable, among which are the preservation of life, and liberty, and the pursuit of happiness.

Thomas Jefferson, Original draft of the Declaration of Independence, 1776.

Equality and independence have been fundamental elements of the American form of government since its inception. The rights to equality of opportunity and to personal independence have been recognized and protected in the Declaration of Independence, the Constitution of the United States, the Constitutions of the individual States, and in the laws enacted by the U.S. Congress and by the States.

Consistent with their central importance to all Americans, the themes of equality and independence have been a major focus of the Nation's policy toward individuals with disabilities. Regarding Federal programs that assist individuals with disabilities, President Reagan has stated:

> *We believe equal opportunity, equal access, and greater economic independence must be more than slogans. . . . By returning to our traditional values of self-reliance, human dignity, and independence, we can find the solution together. We can help replace chaos with order in Federal programs, and we can promote opportunity and offer the promise of sharing the joys and responsibilities of community life.*
> *(President Reagan, Remarks on Signing Proclamation 5131, Establishing the National Decade of Disabled Persons, Nov. 28, 1983)*

In the proclamation establishing the National Decade of Disabled Persons, the President further declared:

> *We must encourage the provision of rehabilitation and other comprehensive services oriented toward independence within the context of family and community. For only through opportunities to use the full range of their potential will our disabled citizens attain the independence and dignity that are their due.*
> *(President Reagan, Presidential Proclamation 5131, November 28, 1983)*

Congress has also endorsed concepts of independence and equality of opportunity for persons with disabilities. It has declared:

> *It is of critical importance to this Nation that equality of opportunity, equal access to all aspects of society and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps; . . . it is essential . . . that all individuals with*

handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective.
(29 U.S.C. section 701 Note (1976))

With broad bipartisan support, Congress has enacted and authorized funding for such programs as Vocational Rehabilitation and the Education for All Handicapped Children Act, which provide concrete initiatives enabling many persons with disabilities to achieve independence and access to opportunities. In 1978, as part of a broadened approach to rehabilitation, Congress established a program of "Comprehensive Services for Independent Living" to provide grants to the States for the establishment and operation of independent living centers (29 U.S.C. sections 796 and 796e).

In addition to the Executive and Legislative Branches of Government, the United States Supreme Court has recognized "the federal interest in developing the opportunities for all individuals with handicaps to live full and independent lives" (*Community Television of Southern Cal. v. Gottfried*, 459 U.S. 498, 508 (1983)).

In furtherance of these Federal interests in independence and equality of opportunity, Congress has directed the National Council on the Handicapped to perform the several assessments contained in this report—assessments of the extent to which Federal programs: (a) provide incentives or disincentives to the establishment of community-based services for individuals with disabilities; (b) promote the full integration of such individuals in the community, in schools, and in the workplace; and (c) contribute to the independence and dignity of such individuals. The national goals concurred in by the President and the Congress have been clearly stated. The remainder of this report assesses the degree to which Federal programs conform to these objectives, and proposes modifications and redirections of such programs to correct those that are deviating from the Nation's goals regarding people with disabilities.

Current Priorities in Federal Programs

Congress has requested that the Council develop a listing, based upon annual expenditures and numbers of persons with disabilities served, of the major Federal programs assisting individuals with disabilities. Such a list is set out beginning on page 55 of this report. A total of 45 programs are listed and briefly described. From the detailed listing, statistical information about persons with disabilities, and the Council's analysis of Federal programs, a few general observations can be made.

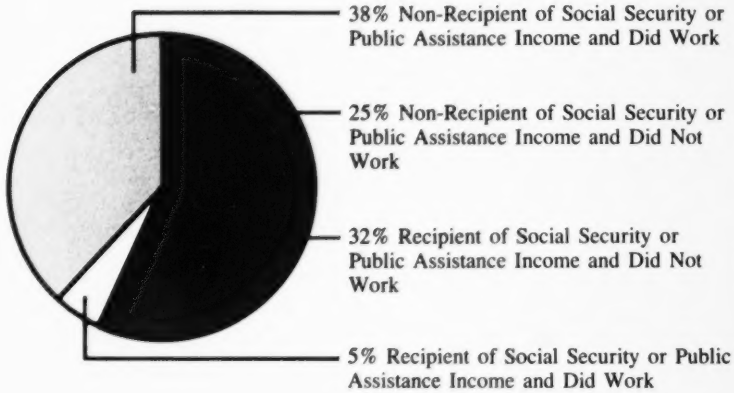
1. Approximately two-thirds of working age persons with disabilities do not receive Social Security or other public assistance income.

Data contradict popular misconceptions concerning the proportion of people with disabilities who are unable to work and are dependent upon public assistance for support. A relatively small segment of the population with disabilities receives income support from programs such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) or other public aid programs.

According to 1980 Census figures, 38 percent of the noninstitutionalized working-age persons who reported a work disability were, nonetheless, employed in the labor market and did not receive Social Security or other forms of public assistance. Twenty-five percent did not work, but did not receive Federal Social Security or any other form of public assistance. Most such persons who neither worked nor received public aid presumably relied for support upon their families, spouses, pensions, private assistance programs, or other similar sources. Thirty-two percent of the working age individuals who reported a work disability did not work during the Census year and received Federal SSI or SSDI benefits or some other form of public assistance. (Another 5 percent worked at some time during the Census year and also received some form of public assistance income.) The interplay of work disability, employment, and public assistance is illustrated in Chart 2.

As Chart 2 indicates, roughly two-thirds of the population with disabilities did not receive SSI, SSDI, or any other form of public assistance during the Census year. Moreover, these percentages are only of the persons who identify themselves as having a ***work disability***; many other Americans having conditions or impairments that would cause them to be termed "disabled" or "handicapped" in common parlance do not identify themselves as having a disability that affects their ability to work. Consequently, the actual percentage of persons with disabilities who are employed and self-supporting is quite probably higher, and the proportion of persons with disabilities who receive income support is probably even lower than indicated by the Census figures.

Chart 2: Persons Aged 16–64 With Work Disabilities by Work Status and Receipt of Either Social Security or Public Assistance (Total = 12.9 Million)


38% Non-Recipient of Social Security or Public Assistance Income and Did Work
25% Non-Recipient of Social Security or Public Assistance Income and Did Not Work
32% Recipient of Social Security or Public Assistance Income and Did Not Work
5% Recipient of Social Security or Public Assistance Income and Did Work

2. ***Federal disability programs reflect an overemphasis on income support and an underemphasis of initiatives for equal opportunity, independence, prevention, and self-sufficiency.***

Although there are certainly gaps in some existing programs and some persons who need and are eligible for public disability benefits who do not get them, the Council believes that such shortcomings are overshadowed by a more serious misdirection of much of the aid that ***is*** provided, of the type and implications for those persons who ***are*** being served under current programs. Public assistance is surely necessary and proper to assist persons whose impairments are severe and who are unable to be self-sufficient, but the Council believes that increased priority should be given to the removal of barriers and disincentives that prevent or inhibit people from moving off such income support benefits to achieve self-sufficiency and independence.

From the listing of Federal programs affecting persons with disabilities (pp.55-65 of this report and foldout chart), it is readily apparent that most of the funds expended by the Federal Government on disability are for public assistance programs. The first six programs in order of expenditures, and ten of the first twelve, are public aid programs. Together, these ten large programs account for over 57 billion dollars in estimated FY 1986 outlays. Most of these programs are premised upon the dependency of the people who receive benefits, in the sense that they

are not self-supporting. Eligibility is based upon inability to engage in substantial gainful activity, or significantly low income. In particular, SSI, SSDI, Medicaid, and Medicare require applicants with disabilities to demonstrate that they are not self-supporting.

The Council does not suggest that such public assistance programs be preemptively terminated or cut back, nor that individuals appropriately receiving such benefits be "pushed off the rolls." The Council proposes, rather, that a redirection of certain Federal programs, as described in its detailed recommendations in this report, can reduce the barriers to opportunity and independence for people with disabilities, allowing many more people with disabilities to remove themselves from Federal aid programs by achieving self-sufficiency and independence.

3. More emphasis should be given to Federal programs encouraging and assisting private sector efforts to promote opportunities and independence for individuals with disabilities.

In recent years, there have been some promising programs in the private sector to remove barriers and achieve participation by persons with disabilities. Many private companies have begun programs to hire and advance employees with disabilities. In 1985, the President's Committee on Employment of the Handicapped and the Dole Foundation published a booklet, *Disabled Americans at Work*, that chronicles efforts of many of America's major corporations to train and employ workers with disabilities.

Business leaders such as David T. Kearns, the president of Xerox Corporation, have spoken out in favor of "full participation" for citizens with disabilities, arguing that business has an economic stake in helping individuals with disabilities become employed and in taking advantage of the pool of potential talent that they represent (Gatty, 1981, p. 3). E. I. du Pont de Nemours and Company has made a point of recruiting employees with disabilities and has monitored their numbers and progress in the company. DuPont has achieved a reputation as an exemplary employer of people with disabilities, and the company's reports are replete with examples of successful case stories (DuPont, 1981, pp. 10–16). In addition to Xerox and DuPont, other major companies making similar efforts to promote the employment of persons with disabilities include AT&T; the Prudential Insurance Company; Sears, Roebuck and Company; Levi Strauss and Company; IBM; and Control Data Corporation, to name but a few (Gatty, 1981, pp. 30–35). Recently, Levi Strauss and McDonald's have been among the companies whose national television advertising campaigns have featured people with disabilities portrayed in a natural, positive context.

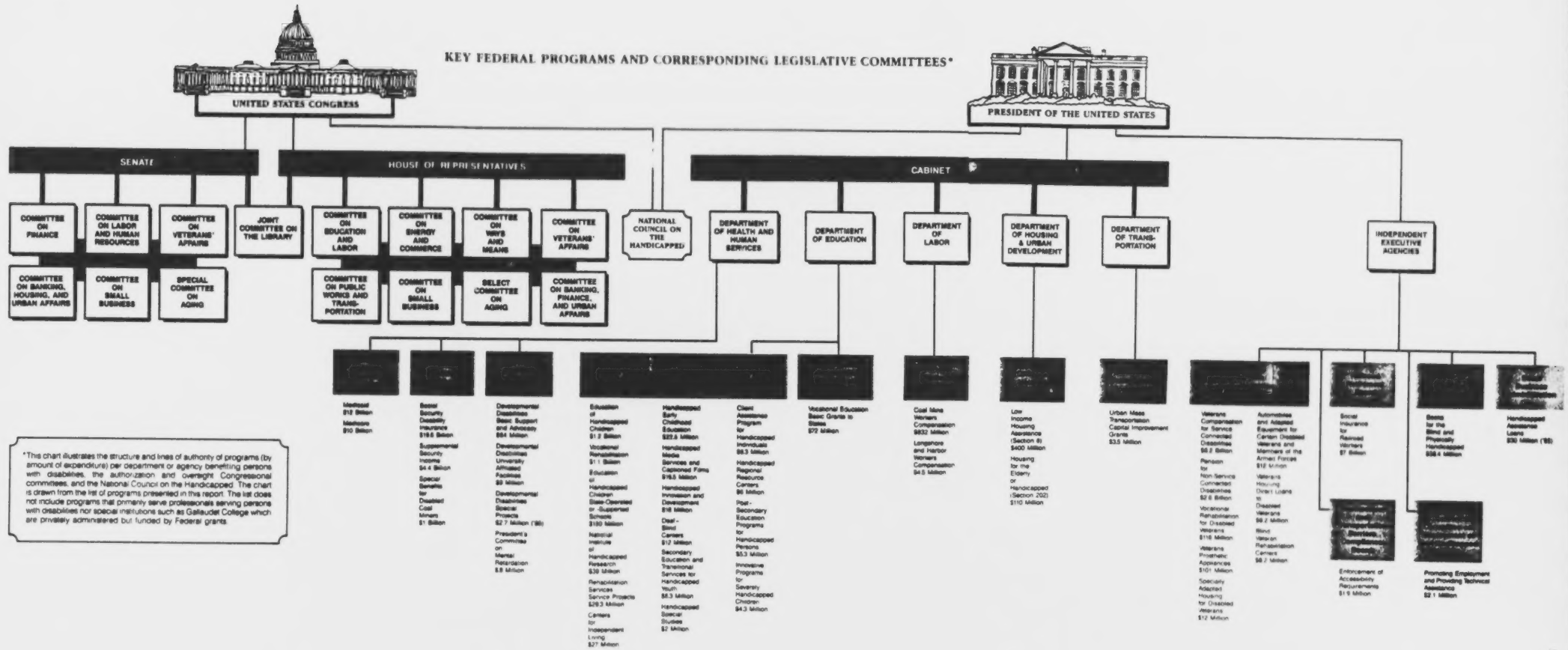
A few Federal programs have encouraged and supported such private sector efforts. Some successful Federal/State rehabilitation agencies have worked very closely in a cooperative partnership with private businesses

to provide training and employment opportunities for individuals with disabilities. The Job Accommodation Network (JAN), operated as a joint venture of the President's Committee on Employment of the Handicapped, the National Institute of Handicapped Research, the Rehabilitation Services Administration, and the West Virginia University Rehabilitation Research and Training Center, is another example of a Federally initiated program that supports private sector efforts to increase the opportunities available to citizens with disabilities. JAN provides a computerized system for obtaining information about practical accommodations that employers can make to enhance job opportunities for employees with disabilities.

Congress has provided some limited financial incentives to private businesses for removing barriers and increasing opportunities for individuals with disabilities, through such programs as the Targeted Jobs Tax Credit (which provides a tax credit for employing workers with disabilities) and Section 190 of the Internal Revenue Code (which allows a tax deduction for the removal of architectural barriers). Congress has also created the Projects with Industry program, which in 1984 spent nearly 14 million dollars through cooperative agreements with business and industry to develop job opportunities for people with disabilities in the competitive marketplace (at an average cost per actual placement of about $1,500).

In spite of these few examples, however, an examination of the major Federal disability programs reveals very little effort to encourage, expand, or strengthen Federal/private sector partnerships that address disability problems. Federal efforts to assist individuals with disabilities should increase their support for promising private sector programs and cooperative governmental/private partnerships that promote increased opportunities and independence for people with disabilities.

KEY FEDERAL PROGRAMS AND CORRESPONDING LEGISLATIVE COMMITTEES*


UNITED STATES CONGRESS
PRESIDENT OF THE UNITED STATES
SENATE
HOUSE OF REPRESENTATIVES
CABINET
COMMITTEE ON FINANCE
COMMITTEE ON LABOR AND HUMAN RESOURCES
COMMITTEE ON VETERANS' AFFAIRS
JOINT COMMITTEE ON THE LIBRARY
COMMITTEE ON BANKING, HOUSING, AND URBAN AFFAIRS
COMMITTEE ON SMALL BUSINESS
SPECIAL COMMITTEE ON AGING
COMMITTEE ON EDUCATION AND LABOR
COMMITTEE ON ENERGY AND COMMERCE
COMMITTEE ON WAYS AND MEANS
COMMITTEE ON VETERANS' AFFAIRS
COMMITTEE ON PUBLIC WORKS AND TRANSPORTATION
COMMITTEE ON SMALL BUSINESS
SELECT COMMITTEE ON AGING
COMMITTEE ON BANKING, FINANCE, AND URBAN AFFAIRS
NATIONAL COUNCIL ON THE HANDICAPPED
DEPARTMENT OF HEALTH AND HUMAN SERVICES
DEPARTMENT OF EDUCATION
DEPARTMENT OF LABOR
DEPARTMENT OF HOUSING & URBAN DEVELOPMENT
DEPARTMENT OF TRANSPORTATION
INDEPENDENT EXECUTIVE AGENCIES
Medicaid $12 Billion
Medicare $10 Billion
Basic Security Disability Insurance $19.5 Billion
Supplemental Security Income $4.4 Billion
Special Benefits for Disabled Coal Miners $1 Billion
Developmental Disabilities Basic Support and Advocacy $64 Million
Developmental Disabilities University Affiliated Facilities $9 Million
Developmental Disabilities Special Projects $27 Million ('86)
President's Committee on Mental Retardation $.8 Million
Education of Handicapped Children $1.2 Billion
Vocational Rehabilitation $1.1 Billion
Education of Handicapped Children State-Operated or -Supported Schools $180 Million
National Institute of Handicapped Research $30 Million
Rehabilitation Services Service Projects $78.3 Million
Centers for Independent Living $27 Million
Handicapped Early Childhood Education $22.6 Million
Handicapped Media Services and Captioned Films $19.5 Million
Handicapped Innovation and Development $18 Million
Deaf-Blind Centers $12 Million
Secondary Education and Transitional Services for Handicapped Youth $8.3 Million
Handicapped Special Studies $2 Million
Client Assistance Program for Handicapped Individuals $8.3 Million
Handicapped Regional Resource Centers $6 Million
Post-Secondary Education Programs for Handicapped Persons $5.3 Million
Innovative Programs for Severely Handicapped Children $4.3 Million
Vocational Education Basic Grants to States $72 Million
Coal Mine Workers Compensation $632 Million
Longshore and Harbor Workers Compensation $4.5 Million
Low Income Housing Assistance (Section 8) $400 Million
Housing for the Elderly or Handicapped (Section 202) $110 Million
Urban Mass Transportation Capital Improvement Grants $3.5 Million
Veterans Compensation for Service Connected Disabilities $8.2 Billion
Pension for Non-Service Connected Disabilities $2.6 Billion
Vocational Rehabilitation for Disabled Veterans $116 Million
Veterans Prosthetic Appliances $101 Million
Specially Adapted Housing for Disabled Veterans $12 Million
Automobiles and Adapted Equipment for Certain Disabled Veterans and Members of the Armed Forces $12 Million
Veterans Housing Direct Loans to Disabled Veterans $6.2 Million
Blind Veteran Rehabilitation Centers $6.2 Million
Social Insurance for Railroad Workers $7 Billion
Enforcement of Accessibility Requirements $1.5 Million
Grants for the Blind and Physically Handicapped $38.4 Million
Promoting Employment and Providing Technical Assistance $2.1 Million
Handicapped Assistance Loans $30 Million ('86)

*This chart illustrates the structure and lines of authority of programs (by amount of expenditure) per department or agency benefiting persons with disabilities, the authorization and oversight Congressional committees, and the National Council on the Handicapped. The chart is drawn from the list of programs presented in this report. The list does not include programs that primarily serve professionals serving persons with disabilities nor special institutions such as Gallaudet College which are privately administered but funded by Federal grants.

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Analysis of Federal Programs in Specific Topic Areas With Legislative Recommendations

The Council has focused its attention upon ten major topic areas of Federal programs affecting people with disabilities. The topic areas are:

- Equal Opportunity Laws
- Employment
- Disincentives to Work Under Social Security Laws
- Prevention of Disabilities
- Transportation
- Housing
- Community-Based Services for Independent Living
- Educating Children With Disabilities
- Personal Assistance: Attendant Services, Readers, and Interpreters
- Coordination

Each of these topics has been the subject of detailed discussion and analysis in individual topic papers contained in the separate Appendix section of this report. They represent areas of critical importance to people with disabilities in which current Federal programs fail to adequately promote national goals regarding individuals with disabilities, and in which redirective or alternative approaches are called for. The topic areas were selected in the interest of producing a manageable and timely report to the President and the Congress with concrete legislative recommendations, but the Council is quite aware of many other important issues affecting people with disabilities that will command the Council's attention in the future and that may call for legislative solutions. The Council expects to issue subsequent reports to address topics and issues affecting classes of people with disabilities, as well as to monitor the implementation of the recommendations made herein.

The major conclusions and legislative recommendations of the Council regarding the ten topic areas follow.

Equal Opportunity Laws

If the goals of independence and access to opportunities for people with disabilities are to be achieved, it is essential that unfair and unnecessary barriers and discrimination not be allowed to block the way. Accordingly, the President and the Congress have called upon our Nation to guarantee equal opportunities for citizens with disabilities. Congress has enacted several laws prohibiting discrimination against people with disabilities. One of the best known of such laws is Section 504 of the Rehabilitation Act of 1973, as amended, which prohibits discrimination on the basis of handicap in programs and activities conducted by the Federal Government or conducted by recipients of Federal financial assistance. Section 503 of the Rehabilitation Act requires Federal Government contractors to take "affirmative action" to employ and advance workers with disabilities. Section 501 places a similar "affirmative action" requirement upon Federal Government employment. Several other Federal laws prohibit discrimination on the basis of handicap in certain other contexts.

A problem with existing laws, however, is that their coverage is not nearly as broad as laws prohibiting discrimination on the basis of race, color, sex, religion, or national origin. Many types of activities, such as employment by agencies engaged in interstate commerce, public accommodations, and housing, are covered by laws prohibiting other types of discrimination, but not by laws prohibiting handicap discrimination. Because of their narrow coverage, handicap nondiscrimination laws fail to serve the central purpose of any human rights law—providing a strong statement of a societal imperative. An adequate equal opportunity law for persons with disabilities will seek to obtain the voluntary compliance of the great majority of law-abiding citizens by notifying them that discrimination against persons with disabilities will no longer be tolerated by our society.

Other problems with current statutes addressing discrimination on the basis of handicap include certain difficulties in the statutory language, the lack of specificity or standards concerning nondiscrimination, and inconsistencies in interpretation and application of the statutes.

Recommendations

1. ***Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.***

Such a statute should be packaged as a single comprehensive bill, perhaps under such a title as "The Americans with Disabilities Act of 1986." The recommendations which follow spell out more specifically the components which such a bill should contain in order to create a comprehensive and effective equal opportunity law for individuals with disabilities.

2. ***The equal opportunity law for persons with disabilities should prohibit discrimination on the basis of handicap by:***

   a. *The Federal Government, all of its agencies and departments, and the United States Postal Service.*

   b. *All recipients of Federal financial assistance, with coverage of all operations of the recipient and not just a particular program or activity.*

   c. *Federal contractors and subcontractors and Federal licensees.*

   d. *All employers engaged in an industry affecting commerce who have fifteen or more employees; employment agencies; and labor unions.*

   e. *All sellers, landlords, and other providers of housing covered by Title VIII of the Civil Rights Act of 1968.*

   f. *All public accommodations covered by Title II of the Civil Rights Act of 1964.*

   g. *All persons, companies, and agencies that engage in the business of interstate transportation of persons, goods, documents, or data.*

   h. *All persons, companies, and agencies that make use of the mails or interstate communications and telecommunications services for the business of selling, arranging, or providing insurance.*

   i. *States, counties, and local governments, pursuant to Congressional authority to enact legislation abrogating the States' immunity under the Eleventh Amendment in order to enforce the Fourteenth Amendment guarantee of Equal Protection of the Laws.*

These provisions would expand coverage of equal opportunity law for people with disabilities to make it commensurate with the coverage of other types of nondiscrimination laws and to apply its coverage to certain particularly problematic types of discrimination against persons with disabilities. In addition, they would undo limitations imposed upon the coverage of such laws as a result of court decisions restricting their application.

3. ***The law should provide a clear definition and standards for applying the prohibition of discrimination on the basis of handicap.***

The statute should straightforwardly prohibit "discrimination on the basis of handicap," without establishing any eligibility classification for the coverage of the statute. Discrimination on the basis of handicap should be broadly construed to apply the requirements of the statute to all situations in which a person is subjected to unfair or unnecessary exclusion or disadvantage because of some mental or physical impairment, perceived impairment, or history of impairment. Discrimination should be defined to include: a) Intentional exclusion; b) Unintentional exclusion; c) Segregation; d) Unequal or inferior services, benefits, or activities; e) Less effective services, benefits, or activities; and f) The use of screening criteria with a disparate impact upon individuals with

disabilities that do not correlate with actual ability. The nondiscrimination requirement should expressly include a duty to make reasonable accommodations, which should be defined as providing or modifying devices, services, or facilities, or changing practices or procedures in order to allow a particular person to participate in a particular program, activity, or job. The duty not to discriminate should also include an obligation to remove architectural, transportation, and communication barriers, including meeting the accessibility requirements recommended below. In addition, there should be a requirement of eliminating discriminatory qualifications standards, selection criteria, and eligibility requirements, with a delineation of the standards and legal tests to be used to determine when such qualifications, criteria, and requirements constitute discrimination. In addition, a requirement of outreach and recruitment efforts should be explicitly established; the focus of such efforts should be upon people with serious disabilities, such as the Equal Employment Opportunity Commission's current listing of "targeted disabilities."

4. ***The law should delineate specific enforcement standards, procedures, and timelines for the implementation of equal opportunity requirements.***

The agencies responsible for developing regulations implementing the equal opportunity law for people with disabilities should be clearly designated, and timelines established for the issuance, after public comment, of such regulations. The Architectural and Transportation Barriers Compliance Board should be directed to establish binding minimum guidelines for architectural, transportation, and communication accessibility, as discussed below in Recommendation 5. Consistent with such minimum guidelines, the Department of Housing and Urban Development should be directed to develop appropriate regulations concerning housing opportunities (for further discussion, see the Council's recommendations on Housing); the Department of Transportation should be directed to develop regulations for mass transit, air travel, and other modes of transportation covered by the law (for further discussion, see the Council's recommendations on Transportation); the Federal Communications Commission should be directed to promulgate regulations governing its licensees; and other agencies should be directed to develop regulations for the areas of their responsibility, including the programs and activities they conduct, those they license, and those for which they provide financial assistance. The Equal Employment Opportunity Commission should expressly be charged with the development of regulations governing Federal employment and for setting standards for all other employment covered by the law. An administrative enforcement process should be provided for individuals who believe that their rights under the law and regulations have been violated. Successful complainants should be entitled to injunctive relief, monetary damages, attorneys fees, and back pay as necessary to remedy the discrimination to which they have been subjected. A private right of action in Federal court should be established for

complainants if administrative enforcement has not occurred after a specified amount of time (e.g., 60 or 90 days), and at the completion of the administrative decision-making and appeals process. The law should authorize the imposition of fines or the cutoff of Federal funds (including both grants and contracts) if there is a showing of discrimination in an appropriate administrative or judicial proceeding; such fines or funding cutoff should continue until the discrimination is corrected or discontinued.

5. ***The Architectural and Transportation Barriers Compliance Board should be given the authority and responsibility to issue minimum guidelines for universal accessibility and other standards for the removal of architectural, transportation, and communication barriers in facilities, vehicles, programs, and activities covered by the equal opportunity law for people with disabilities.***

This recommendation is intended to correct the problems with the language of Section 502 of the Rehabilitation Act of 1973 as currently worded that have left questions about the extent of the authority of the Architectural and Transportation Barriers Compliance Board (ATBCB) to set minimum guidelines regarding transportation and communication barriers. It would also expand the Board's authority commensurate with the expanded coverage of the equal opportunity law recommended in this report. Provisions establishing ATBCB should also be amended to provide that public members of the Board shall continue to serve at the expiration of their terms until their successors have been appointed and are ready to serve.

6. ***The law should also:***

   a. *Direct the Federal Government to use its leverage as a consumer of goods and services to require that businesses and companies from which it rents or makes purchases to make goods, services, and facilities usable by individuals with disabilities;*

   b. *Apply to discrimination in medical services;*

   c. *Include an enforceable Bill of Rights for Persons with Disabilities;*

   d. *Provide for the dissemination to persons with disabilities of information concerning their rights;*

   e. *Provide a private right of action against Federal contractors and subcontractors who engage in discrimination against people with disabilities; and*

   f. *Provide an expanded Protection and Advocacy System in each State to protect and advocate for the rights of individuals with all types of disabilities, regardless of age of onset.*

Employment

As for most other Americans, a major prerequisite to economic self-sufficiency for individuals with disabilities is a job. Employment is an essential key to successful adult integration into community life. Various forms of work are associated with greater independence, productivity, social status, and financial security. Success and quality of life are often measured in terms of paid employment.

Studies indicate that only one-third of youths with disabilities leaving school graduate to a job or some form of advanced education. The absence of a systematic vocational transition process for youths with disabilities significantly contributes to the unemployment rates of persons with disabilities. Of the approximately 12.9 million working age persons reporting a work disability, only 4.2 million (or 32 percent) were working at the time of the 1980 Census.

Reasons for high unemployment and underemployment among persons with disabilities include the lack of an effective transition process from school to work for youths with disabilities; societal attitudes which cause employers to discriminate against persons with disabilities; physical and communication barriers in buildings, transportation, and worksites; and the lack of appropriate training opportunities for persons with disabilities.

State/Federal vocational rehabilitation agencies, projects with industry, return-to-work programs (established by some businesses), and selective hiring authorities within the Federal Government have increased employment opportunities for persons with disabilities. Although programs such as these encourage education and employment, they are inadequately meeting the goal of successfully integrating persons with disabilities in schools, workplaces, and the community.

To increase employment opportunities for people with disabilities, programmatic changes are needed in several areas.

Recommendations

Transition

1. ***Congress should direct the Department of Education to designate the State educational agency as the lead agency to start, develop, and carry out the transition planning process.***

This Nation has invested heavily in special education; to capitalize on this investment, it is necessary for the Federal Government to assure that each youth in a special education program be guaranteed a well-developed, organized and coordinated transition process from school to work.

The regulations accompanying Public Law No. 94-142, the Education for All Handicapped Children Act, should be modified to make the State education agency responsible for the transition process. The State and local education agencies should be responsible for initiating and carrying out the transition process, including contacting the appropriate

personnel in regular and special education, vocational education, vocational rehabilitation, community colleges, developmental disabilities and other agencies from whom each student receives services. To support this effort, the regulations should set the following minimum guidelines:

- The planning process should begin no later than ninth grade, and should include the active involvement of parents and students.
- A formal written plan with long- and short-term goals and objectives that include functional skills for employment and daily living is to be prepared and updated annually by the lead agency in consultation with the student, parents, and other involved agencies. Parent and student approval of the plan should be required in writing.

2. ***Congress should direct the Department of Education to strengthen regulations requiring the involvement of education coordinators and vocational rehabilitation counselors in the transition process.***

Vocational rehabilitation counselors and education coordinators (including general, special, and vocational education) should be actively involved in the transition process. In addition to prescribing such participation, the regulations should provide minimum standards for the training of vocational rehabilitation counselors and education coordinators in regard to the transition process. Training should focus on strategies for involving employers and families in the transition process, as well as eligibility requirements, and pertinent special education and vocational education techniques. These training requirements, coupled with the State education agency taking the lead for transition services (Recommendation 1, above), will establish the foundations for a coordinated transition process. These recommendations can be implemented without additional expenditures of public funds.

Supported Work

3. ***Congress should amend the Rehabilitation Act to add a Title expressly authorizing programs of supported work for persons with severe disabilities who can be competitively employed with the assistance of such a program.***

The term "supported employment" means paid employment which: a) is for persons with severe disabilities (such as developmental disabilities, chronic mental illness, and severe physical disabilities) for whom competitive employment at or above the minimum wage without support is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting; b) is conducted in a variety of settings, including worksites in which persons without disabilities are employed; and c) is supported by any activity needed to sustain paid work by persons with disabilities, including supervision, training, and transportation.

If supported work programs were available, a large number of severely disabled persons residing in residential facilities could return to the

community and become gainfully employed. Some pertinent figures indicate:

- 499,169 persons with mental illness were served in 277 state hospitals for $4.5 billion (Goldman, Gattozzi, and Taube, 1981).
- 243,669 persons with mental retardation were served in 15,633 residential facilities for $5.9 billion (Smith, 1984).
- 1,396,132 elderly and physically disabled persons resided in 23,065 nursing homes (Sirrocco, 1983) and other long-term care facilities at a cost to Medicaid of $12.4 billion (National Study Group on State Medicaid Strategies, 1983).

If permanent authorization and funding for supported work programs were in place under the Rehabilitation Act, these numbers could be significantly reduced. Congress appropriated $3.7 million in FY 1985 for grants for supported work programs. Permanent funding is needed to sustain these supported work activities and to develop others.

Funding for supported work programs will provide persons with severe disabilities an opportunity to work toward independence by becoming taxpayers rather than remaining dependent upon other taxpayers. Implementing this recommendation should not entail expenditures of additional public funds. For example, the Medicaid payment process could be modified to allow the funds a disabled person receives while in an institution to follow or accompany the person to the community to pay for educational and vocational services including supported work. Medicaid payments for individuals employed in supported work situations should be much less than if such people remained in institutions. Likewise, the Title XX program funds day activity programs for severely disabled persons not eligible for vocational rehabilitation services. Some portion of funds from this program should be re-directed to provide supported work services for this population, since studies show that many severely handicapped individuals are capable of productive work if given appropriate support services. This change would not involve an increase in funds or an increase in persons served. Rather, day activity programs would simply be encouraged to provide vocational services as part of their programming.

Federal Support for Private Sector Initiatives

4. Congress should extend and expand the Targeted Jobs Tax Credit Program (Deficit Reform Act of 1984).

The Targeted Jobs Tax Credit (TJTC) Program should be made permanent with greater first year tax credit allowances. The TJTC Program should expressly authorize employer tax credits for: reemploying persons who become disabled on the job, hiring disabled persons in higher than entry level positions, and assisting disabled employees who must relocate. Credits should also be allowed for training disabled employees in high demand technical areas.

The existing TJTC Program gives employers a financial incentive to provide disabled job seekers an opportunity to demonstrate their capabilities. The recommendation to extend and expand this program should result in a net benefit to the Federal Treasury because the taxes paid by disabled employees assisted by the program should greatly exceed the tax credits allowed to employers. In FY 1984, according to the Department of Labor, 38,263 disabled persons were certified under the TJTC Program.

5. Congress should make Section 190 of the Internal Revenue Code permanent and expand it to a maximum amount of $75,000 per year.

Section 190 encourages accessibility and increases employment opportunities for persons with disabilities by allowing a tax deduction for the removal of architectural barriers. This incentive encourages employers to hire persons with disabilities and elderly people for jobs suited to their needs and talents. Before these individuals can become full working members of society, the workplace must be accessible.

6. Congress should develop innovative and effective incentives to promote the establishment of return-to-work programs.

Incentives should be developed to promote the establishment of return-to-work programs by employers. Return-to-work programs provide early intervention services (counseling, job analysis, etc.) for employees who may become disabled by an injury or illness.

According to Hood and Downs (1985), on-job accidents burdened the 1982 economy with an estimated $31.7 billion in direct and indirect costs. After adding the $24.9 billion cost of off-job accidents (about one-third of which was borne by employers), the 1982 total cost of accidents was $56.6 billion. During that year an estimated 100 million lost work days resulted from disabling injuries and another 40 million lost days were caused by disabilities from prior years.

Effective return-to-work programs will reduce the cost of health and income maintenance programs by reducing the number of persons with disabilities who are not working. Effective return-to-work programs have been established by businesses such as Minnesota Mining and Manufacturing Company, Eastman Kodak, and Control Data.

Job Development and Placement

7. Congress should support the development of area model centers on employment for persons with disabilities.

Model centers on employment for persons with disabilities should be established to demonstrate and disseminate information about innovative or "cutting edge" employment strategies. The functions of the centers would include: job analysis; job restructuring; dissemination of

state-of-the-art information on employment strategies, vocational evaluation, models for coordination of special education, rehabilitation, and vocational education, job development, and placement.

These model centers could be developed through a cooperative effort of the Department of Labor, the National Institute of Handicapped Research, the Rehabilitation Services Administration (RSA), State and local governments, and the private sector, with RSA having the lead role in establishing and operating the centers.

Job Training

8. ***Congress should amend the Job Training Partnership Act (JTPA) to eliminate the income eligibility requirement for persons with disabilities and to increase the representation of persons with disabilities on Private Industry Councils.***

Although the current JTPA legislation helps to increase the employment and decrease the dependency of disabled persons, it has shortcomings. Disabled persons are not being adequately served by JTPA because unlike its predecessor, the Comprehensive Employment and Training Act, JTPA does not consider a person eligible because his/her handicap constitutes a barrier to employment. Income eligibility criteria must be satisfied in order to receive services. In addition, few individuals who understand the needs of persons with disabilities are represented on the Private Industry Councils that direct local JTPA programs. For this legislation to be of substantial benefit to disabled pesons, the Department of Labor should ensure that:

- The State Job Training Coordination Councils and the local Private Industry Councils include people who understand the needs, capacities and capabilities of disabled persons, particularly including persons who themselves have disabilities.
- State and local plans have provisions for projects that address the needs of disabled persons.
- Councils place a priority upon and develop methods for achieving the participation of disabled persons in their programs.
- JTPA programs have vocational education and vocational rehabilitation components.
- Parents and educators are informed of the programs available for people with disabilities.
- Data is collected on the number and percentage of disabled persons served.

Disincentives To Work Under Social Security Laws

The recommendations in the previous section focused upon increasing the effectiveness of Federal efforts to secure employment opportunities for individuals with disabilities, thus increasing the chances for such individuals to achieve independence and economic self-sufficiency. Some Federal programs under current Social Security laws not only fail to promote employment and independence for citizens with disabilities, but actually penalize and discourage people with disabilities if they seek to become employed. These programs—Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid and Medicare—provide many severely disabled people with basic life necessities. Consumer and service provider experiences indicate, however, that some program provisions encourage dependence and discourage gainful employment.

Currently the Social Security Administration's (SSA) process for determining eligibility for SSI or SSDI income benefits begins with a medical evaluation of the individual's disability. Only in cases in which the disability is not on the SSA "medical list" (e.g., blindness, deafness, spinal cord injuries), does the eligibility determination include both a medical diagnosis and an assessment of vocational potential. This determination process can sometimes result in the automatic award of benefits to individuals with clearly defined medical disabilities who have significant vocational potential and should be able to work.

A major disincentive to work for many current SSI and SSDI recipients is that employment in many entry level and low paying service jobs will often result in reduced income and the loss of medical and other benefits. The Council also finds evidence that many people with preexisting medical conditions cannot obtain adequate health insurance at an affordable cost. This problem creates an incentive to enter public aid programs since the medical costs associated with some disabling and preexisting conditions exceed the working individual's ability to pay.

Recommendations

1. Congress should amend the Social Security Act to make eligibility for SSI and SSDI programs dependent upon the presence of a severe medical disability and a functional assessment to determine vocational potential whenever deemed appropriate.

Whenever the vocational potential of a working age applicant is at issue, applicants who are not terminally ill should be required to undergo a functional vocational assessment that establishes that they will have substantial difficulty working because of severe vocational limitations of an ongoing nature. Individuals with disabilities who are refused SSI and SSDI income support benefits because they are determined to be able to work should be offered vocational rehabilitation services.

This recommendation is designed to change the focus of disability determinations from a purely medical standard to one that assesses the full range of factors that affect the ability to work of persons with

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disabilities. It narrows the definition to prevent those who have a medical impairment but are able to work from automatically becoming eligible for income support benefits.

To implement this recommendation, the Social Security Administration should be charged with using its demonstration authority to develop procedures for conducting functional vocational assessments and for assuring that adequately trained people are available to carry out the assessments. For instance, SSA could contract for this service with independent agencies, such as independent living centers, vocational rehabilitation agencies, or colleges and universities. SSA should also enter into cooperative agreements with State vocational rehabilitation agencies to assure that individuals who are refused benefits because of their vocational potential are not then refused vocational rehabilitation services. Applicants should not be required to undergo a second, duplicative vocational assessment if they are referred for vocational rehabilitation services.

2. ***Congress should amend the Social Security Act to assure that SSI and SSDI recipients who become gainfully employed are permitted to retain benefits and have access to medical insurance in circumstances where the loss of such benefits would substantially negate the income they might earn.***

Three steps should be taken to implement this recommendation. First, Section 1619(a)&(b) of the Social Security Act, which authorizes continuing cash benefits and Medicaid coverage to working SSI beneficiaries, should be made permanent, thereby removing the uncertainty associated with the temporary nature of Section 1619.

Second, Section 1619 provisions should be extended to SSDI recipients. The formula for determining benefits when earnings increase may need to be modified since some SSDI recipients receive comparatively high benefit payments. If the Federal break-even point for SSI were used for SSDI, benefits might reach inappropriately high levels.

Third, Medicare and Medicaid coverage should be made available on a sliding fee scale that reflects income to working SSDI and SSI beneficiaries who cannot obtain private health insurance coverage because of their disabilities. Employers should be required to contribute an amount equal to that contributed to other employee health insurance plans. Alternatively, cooperative programs with insurance programs might be developed in which Medicaid would pay disability-related medical expenses and the private insurer would be responsible for other medical expenses.

3. ***Congress should direct the Health Care Financing Administration to study and recommend cost-effective methods for providing health insurance coverage to persons with preexisting conditions who cannot obtain adequate health insurance coverage from private insurers at affordable rates. The study should be conducted in consultation with the National Council on the Handicapped, and findings and recommendations should be reported in hearings before Congress within two years of the date of enactment of this provision.***

Some disabled workers are forced into income support programs primarily because they cannot obtain private medical insurance coverage due to the preexisting conditions of disability. Persons with disabilities who are self-employed often have great difficulty because they rarely have access to a group insurance program. If a disabled worker's income is not sufficient to cover both basic living and medical expenses, the worker may be forced into a public assistance program in order to obtain the needed medical benefits.

The Council believes that the availability of health insurance coverage for people with disabilities is an important incentive to employment, and that the States may be able to provide leadership in this area. Innovative programs in place in those States that provide health insurance coverage for uninsured populations should be examined, and a variety of funding and insurance strategies should be considered.

Considerable savings can be realized by removing disincentives to work in current programs: Medicaid benefit payments often decrease when a person with a disability is employed. Income support payments will always be reduced as recipients of income benefits become gainfully employed and income support benefits are reduced or ended. Although there is no precise method of estimating expected costs and benefits, the Congressional Budget Office has informally estimated that no increases in costs are associated with a permanent extension of Section 1619. Other authorities have projected considerable cost savings. For instance, in August of 1984, 6,000 SSI recipients earned over $713 a month, the break-even point for going off of SSI payments. If permanent, continued Medicaid coverage encouraged these individuals to leave the SSI program, a savings of $324 a month per individual in SSI payments would result in a projected reduction in cash benefits of $23 million per year (Bartlett, 1985). The advantages to society are even greater if personal benefits to the individual, such as increases in self-esteem and mental and physical health, and economic benefits to the community, such as the purchase of goods and services, are considered.

Prevention of Disabilities

A Federal initiative to prevent disability could substantially reduce the health care costs and human suffering associated with the high incidence of disability in this country. Effective preventive measures would reduce the costs of disability and health care for Americans, reduce Federal spending for disability in the near future, and decrease the incidence of disability for future generations.

Studies indicate that preventive measures would greatly reduce the number of new additions to the disabled population. For example, an estimated 50% of hearing impairments could be prevented through the use of inexpensive preventive strategies. A substantial percentage of the serious birth defects and illness experienced each year by approximately 250,000 infants could be prevented through effective prenatal and infant care. Most of the estimated 59 million nonoccupational injuries that occurred in 1981, including the 27 million accidents that occurred in and around the home, could have been prevented. Prevention is inexpensive and painless when compared to the high cost and suffering associated with preventable illnesses and accidents.

Our Nation has the knowledge, technology, and resources to mount an effective and successful national program for the prevention of disabilities. Preventive action could substantially reduce disabilities resulting from: a) infant birth disorders, illness, and injuries; b) vehicular accidents; c) heart disease and stroke; d) occupational accidents and hazards; e) home, recreational and pedestrian accidents; f) genetic disorders; g) infectious diseases; h) chronic diseases; i) toxic substances in the environment; j) noise pollution; k) radiation; and 1) violence. Preventive efforts could also reduce the unnecessary secondary disabilities or exacerbation of impairments often experienced by people with disabilities. In addition, Americans should be encouraged to use healthy lifestyle behaviors which prevent certain types of diseases and disorders.

The Council urges the Federal Government to mount a national program for the prevention of disability by providing leadership and by coordinating Federal prevention-related programs.

Recommendations

1. Congress should enact a law related to prevention entitled "The Prevention of Disabilities Act."

The Act should have three chief provisions: a) authorize the National Council on the Handicapped to establish policy and goals for a National Plan on the Prevention of Disabilities, and to review and make recommendations regarding implementation of the Plan; b) require the Office of Disease Prevention and Health Promotion (Department of Health and Human Services), working with the National Council on the Handicapped and other appropriate Federal agencies, to oversee the development and implementation of the National Plan; and c) authorize a small grant program to support the development of coordinated, comprehensive, and effective prevention programs by States and local communities. The grant

program should be administered by the Assistant Secretary of Health. Implementation of this recommendation should require only a small number of additional staff and some operational funding to support the implementation of Parts a and b above. In addition, the small grant program (Part c) would require only minimal funding support over a five year period.

2. ***Congress should provide appropriate levels of funding for special program priorities related to disability prevention.***

The appropriation of funds for specific program priorities should include: a) prenatal care through the Maternal and Child Health Care program, Medicaid, and the Women, Infants, and Children (WIC) program (at no less than FY 84 levels); b) preschool educational services through block grants to State educational agencies; c) educational programs for professional personnel, parents and children in disability prevention; d) dissemination of information about disability prevention to minority groups, children, and adolescents through public education programs and curriculum units about prevention in elementary and secondary schools; and e) development of methods for preventing secondary disability among those already disabled.

3. ***Congress should direct its Office of Technology Assessment to conduct a study of the status of primary and secondary prevention of disability in the United States, and to submit a report of its findings two years after the issuance of the National Plan on the Prevention of Disabilities.***

The authorization would provide for an objective, independent assessment through the Office of Technology Assessment of the status of primary and secondary prevention efforts in the United States, and of compliance with the National Plan.

Transportation

Another prerequisite for achieving equal opportunities and independent living for persons with disabilities is transportation—the ability to get to and from work, stores, medical facilities, recreational and social settings, and other destinations—to move about the local neighborhood, the city, the state, and the world. The Urban Mass Transit Act, as amended in 1970, established services for disabled people as a basic element of Federal transportation policy—it states that disabled people have the same right to use public transportation as nondisabled persons. Specific language promoting this principle was also included in the Federal-Aid Highway Act of 1973. Since 1970, the nation has begun implementing accessible transportation systems in compliance with this policy.

Approximately 7.4 million persons are transportation-handicapped, according to a national survey conducted by the Department of Transportation. Transportation handicaps vary, ranging from difficulty climbing stairs, reading signs, hearing announcements, or understanding transit information, to the use of a wheelchair. On the average, persons with transportation handicaps have lower incomes than other Americans, and are more dependent on public transportation to conduct the business of their daily lives. In fact, a major impediment to employment for people with disabilities is their inability to reach the job site. Increasing job opportunities through improved access to transportation would bring far-reaching economic benefits to disabled individuals and to society.

Regulations designed to implement legislative requirements for accessible urban transportation systems have changed several times during the past 15 years. They have ranged from minimal "special efforts" and "local options" to requirements based on Section 504 of the Rehabilitation Act of 1973 for almost immediate full accessibility. Current regulatory efforts have begun to concentrate on setting performance criteria for the provision of services to disabled persons. This is intended to assure that services available to disabled persons are equivalent to those available to nondisabled passengers. Specifics of system design would be determined at the local level in response to local conditions and community needs with significant input from disabled and elderly individuals.

The Council has reviewed the implementation of the Nation's transportation policy. Its conclusion is that we are far short of a truly accessible system. A 1982 survey conducted by the General Accounting Office indicated that nearly three-fourths of the urban rail stations surveyed are almost totally inaccessible to wheelchair users. The same study determined that one-third of the transit systems offering fixed-route bus service did not have a single bus with a lift. A 1985 American Public Transit Association (APTA) fact sheet reported that 76% of the 49,000 buses in use in this country are not accessible.

Disabled persons encounter a variety of additional problems when attempting to use other forms of transportation. Air travelers who use wheelchairs face a multitude of problems, ranging from uncomfortable, dangerous, and dehumanizing boarding procedures to inaccessible

restrooms and boarding areas. Intercity/interstate bus service, the primary mode of public transportation for people in rural areas, is almost totally inaccessible to many persons with transportation handicaps. Modified private vehicles, frequently the only source of transportation realistically available to many persons with severe disabilities, are often prohibitively expensive for individuals and families with limited incomes.

Although the general picture currently appears bleak, the Council has identified cost-effective, working models of usable, accessible transportation systems. Seattle, Washington; Champaign-Urbana, Illinois; Dayton, Ohio; Johnstown, Pennsylvania; and Palm Beach, Florida, have made significant and successful efforts to provide accessible public transportation which meets the needs of most of their citizens in a cost-effective manner. In addition, some interstate bus systems have attempted to develop accessible bus service, and some airlines already provide effective, courteous service for persons with travel disabilities. Amtrak has developed a model transition plan for accessibility that looks very promising.

The Council has concluded that accessible transportation is a critical component of a national policy that promotes the self-reliance and self-sufficiency of people with disabilities. People who cannot get to work or to the voting place cannot exercise their rights and obligations as citizens. Accessible transportation will become increasingly important in coming decades as the baby-boom population grows older and experiences the increased transportation handicaps associated with aging.

Providing only "special" van service and modified private vehicles is too expensive and restrictive an option to meet the needs of this growing population, as is retrofitting tomorrow the mass transit systems that are being built or renovated today. The Nation's experience with accessible transportation over the last 15 years suggests that workable cost-effective alternatives are available. The time has come to make our Nation's policy of accessible transportation a reality.

Urban Mass Transit

Recommendations

1. ***Congress should amend Section 16 of the Urban Mass Transit Act to require full accessibility to mass transportation to be achieved over a realistic period of time; such amendments should:***
   a. *Prohibit discrimination on the basis of disability by recipients of Federal funds under this Act.*
   b. *Require recipients to provide a level of service to disabled and elderly persons that is equivalent with that available to nondisabled persons in terms of: 1) service range, 2) transfer frequency, 3) fare, 4) travel purpose, 5) trip decision/travel time, 6) capacity, and 7) availability.*
   c. *Require that all new facilities and vehicles constructed or purchased with funds under this Act be accessible.*
   d. *Require recipients of funds under this Act to develop specific transition plans for achieving, within a reasonable period of time,*

full access and comparable service levels. These plans should be developed with the substantial and meaningful involvement of disabled and elderly consumers.

e. Create a private right of action for persons who believe they have been discriminated against by recipients of funds under this Act.

Full access to transportation can only be accomplished by combining various modes of accessible transportation, including fixed-route buses, specialized services, and rapid rail systems. Such a system can provide to disabled and elderly persons reliable transportation services that are tailored to local conditions, accessible, and equivalent in the quality and level of service to that provided to other citizens. All new facilities and vehicles should be required to be accessible. By making facilities and vehicles accessible at the time of construction or purchase, unnecessary, expensive retrofitting and renovation can be avoided. Disabled and elderly consumers must be involved in substantial and meaningful ways throughout the process of planning, implementing, and evaluating transit systems.

The Council also believes that persons who feel that they have been discriminated against in the provision of transportation should have individual and collective recourse for resolution of their rights through the courts. The potential for court action would also provide a clear incentive to transit authorities to act in nondiscriminatory ways so as to avoid sanctions which might be imposed by a court of law.

2. ***Congress should amend the Architectural Barriers Act of 1968 to establish the Department of Transportation as a standard-setting agency for the development of access standards for buildings, facilities, and public conveyances, including rolling stock and aircraft, which are designed, altered, constructed or purchased with Federal funds to insure that they are readily accessible and usable by disabled and elderly persons.***

The Department of Transportation (DOT) currently sets transportation standards governing such matters as configurations of vehicles, communications access, appropriate signage, and safety. This recommendation will clearly establish DOT as the standard-setting agency for accessible transportation under the Architectural Barriers Act. The required standards, which should be developed with the input of the Council, would set forth specific requirements to guide transit authorities in designing accessible transit systems and evaluating their effectiveness.

Section 502(B) of the Rehabilitation Act of 1973 directs the Architectural and Transportation Barriers Compliance Board (ATBCB) to set minimum guidelines and requirements for standards developed by the standard-setting agencies under the Architectural Barriers Act. The combination of setting standards and establishing minimum guidelines and requirements will provide greater assurance to disabled and elderly persons that transportation systems developed with Federal funds will in fact have access features which make them usable in a meaningful way.

It should be noted that certain technical changes to the initial text of the Architectural Barriers Act would be needed to accommodate the addition of DOT. Thus, coverage of "public conveyances" and things which are "purchased" with Federal funds should be added.

Air Transportation

3. Congress should amend the Federal Aviation Act to:

a. Prohibit discrimination on the basis of disability by all airlines using Federally assisted airports.

b. State that all airlines using Federally assisted airports are subject to the provisions of Section 504 of the Rehabilitation Act of 1973 and regulations promulgated thereunder.

Currently only a few small air carriers are directly Federally subsidized and thus covered by nondiscrimination provisions under Section 504 of the Rehabilitation Act of 1973. These air carriers provide only a small percentage of this Nation's air transportation. To assure accessible air transportation for America's disabled and elderly citizens, Congress should require that all airlines using Federally assisted airports be prohibited from discriminatory practices and be subject to regulations promulgated under Section 504. Airlines should also be required to review and eliminate current practices and policies which have resulted in discriminatory, ineffective, and often dangerous service to disabled and elderly persons. Recommendation 2 above, requiring the Department of Transportation and the Architectural and Transportation Barriers Compliance Board to set standards and minimum guidelines for access, covers the provision of air transportation. This will insure accessible airports and aircraft.

Intercity and Interstate Buses

4. Congress should extend coverage of handicap nondiscrimination requirements to interstate commerce, thus prohibiting such discrimination by intercity and interstate bus companies.

Intercity and interstate bus transportation is often the only form of public transportation connecting people in rural areas with major cities and towns. By prohibiting discrimination and improving access to this type of transportation, many more people would be able to take advantage of the many educational, recreational, and employment opportunities found only in the city. (For further discussion of nondiscrimination provisions, see the section on "Equal Opportunity Laws" above.)

Private Transportation

5. Congress should establish a low-interest loan program based on income to assist disabled persons and families with disabled children or elderly persons to purchase vehicles or to make necessary access modifications.

Private transportation provides the only means by which many disabled and elderly persons can become employed and participate in educational

and recreational programs. In rural areas, private transportation is frequently the only transportation option. Since the cost of purchasing and modifying vehicles is prohibitive for many disabled persons and their families, such a low-interest loan program is needed to supplement the other transportation options outlined above. Federal funding for such a program should be provided up to a reasonable cap amount as established by Congress.

6. ***Congress should direct the Department of Transportation to commission a study, based upon its existing authorities and targeting currently available funds, to assess the impact of increased access to transportation on employment, education, and quality of life for disabled and elderly persons.***

Little current data is available to document the potentially great benefits resulting from accessible transportation. Older studies suggest many benefits, both economically and in terms of life quality, that are associated with access to transportation. The study called for in this recommendation would provide more up-to-date documentation of such individual and societal benefits.

Housing

Securing appropriate housing is a major prerequisite to social integration and living independently for persons with disabilities. The lack of appropriate housing opportunities for individuals with disabilities frequently results in the unnecessary and expensive institutionalization of such persons. Available data suggest that the costs of providing appropriate housing options for disabled people are well worth the investment because of the significant savings that may be engendered by enabling disabled people to live in the community, get jobs, and pay taxes. Various reports of Federal agencies, disabled persons, and the few formal studies of the subject have documented a serious shortage of housing options for people with disabilities.

Congress and the Administration have recognized that private production may not be sufficient to meet the housing needs of elderly persons and persons with disabilities. The only Federal construction and rehabilitation loan program that addresses this shortfall of appropriate housing units is the Section 202 Program administered by the Department of Housing and Urban Development (HUD). The traditional Section 202 Program, however, has engendered certain problems, such as the isolation of persons with disabilities and a lack of age-appropriate social integration. HUD is currently reevaluating the program for possible redirection.

HUD administers two major programs that provide rent subsidies for people with reduced incomes, including those with disabilities. The older of these two programs—the traditional Section 8 Program—provides housing assistance payments for eligible handicapped tenants in rent-subsidized housing. Section 8 subsidies have encouraged housing developers to construct Section 202 housing units because they create assured rent revenues for the units. The second program—the Administration's voucher program—has been initiated as a demonstration project. It appears to be an effective vehicle for providing rent assistance to disabled and other persons with low incomes, while permitting such persons the opportunity to select their own places of residence.

A few local governments have used some of their community development block grant funds to develop housing programs and units for people with disabilities.

The Federal Fair Housing Act—Title VIII of the Civil Rights Act of 1968—prohibits discrimination in housing on the basis of race, color, religion, sex, and national origin, but does not address discrimination on the basis of handicap. As a result, housing providers who are prohibited from discriminating on other grounds are permitted to discriminate against citizens with disabilities. Section 504 of the Rehabilitation Act prohibits discrimination on the basis of handicap by recipients of Federal financial assistance, but no final HUD regulations implementing this requirement have been issued.

Recommendations

1. ***Congress should prohibit housing discrimination against persons with disabilities on as broad a basis as race, color, religion, sex, and national origin discrimination are prohibited under Title VIII of the Civil Rights Act of 1968.***

Recognizing that one of the Nation's largest minorities—that of persons with disabilities—is omitted from the coverage of the Fair Housing Act, the Council recommends expanding coverage of housing nondiscrimination requirements to protect persons with disabilities. This may be accomplished either by amending Title VIII of the Civil Rights Act of 1968 to include "handicap" or by enacting a separate law (for further discussion, see the Council's recommendations on "Equal Opportunity Laws"). President Reagan has called for expansion of Fair Housing legislation to protect people with disabilities, and has noted an apparent Congressional consensus in favor of such an expansion of coverage (President Reagan, Message to the Congress Transmitting Proposed Fair Housing Legislation, July 12, 1983, p. 992).

Such a prohibition should make clear that developers, landlords, and real estate management companies may be required to make reasonable accommodations for individuals with disabilities. It should also encompass a requirement of compliance with full accessibility standards as described in Recommendation 2 below. The statutory prohibition of discrimination in housing should declare local zoning ordinances invalid to the extent that they prevent the establishment or operation of community residential alternatives for people with disabilities in all housing covered by Title VIII.

2. ***Congress should require that all housing units constructed or substantially altered with Federal financial assistance, Federal loans, Federally subsidized or insured loans, or by agencies of the Federal Government, should be required to meet accessibility standards.***

In light of data indicating that such modifications entail a very small percentage of costs of new housing, Federal agencies should implement a plan and develop regulations requiring that all housing units be adaptable, based upon Uniform Federal Accessibility Standards now in effect under the Architechtural Barriers Act of 1968. These standards provide technical specifications for a universally accessible floor plan, e.g., level or ramped entrances, wide doors, lower outlets and heating controls, accessible bathrooms with reinforced walls, accessible kitchens, and lower door knobs and locks. Pursuant to analysis of the costs of the modifications, and pursuant to minimum guidelines that should be established by the Architectural and Transportation Barriers Compliance Board, requirements for adaptability in housing may also impose additional requirements for modifiable accessibility, such as adjustable shelves in closets, and warning devices and flashing lights for people with hearing impairments. This type of universally accessible housing unit would be easily modified to meet the individual needs of a person with a disability. Specific standards for applying such accessibility requirements should be developed with input from the National Council on the Handicapped,

representatives of the housing construction industry, such as the National Association of Home Builders, and organizations of persons with disabilities. HUD should chair a Federal interagency committee to assist and coordinate the development of accessible housing units under the jurisdiction of other Federal agencies, consistent with minimum guidelines established by the Architectural and Transportation Barriers Compliance Board.

Accessible housing is not only an urgent present need for citizens who currently have disabilities, but, as the U.S. population becomes increasingly older with the maturing of the baby-boom generation, accessible housing will become increasingly more important for the growing population of elderly citizens. Statistics are clear: many Americans who do not now have disabilities will incur disabilities in their later years and will find themselves searching for accessible housing. Imposition of an adaptability requirement on housing construction today is one important step toward addressing the growing need for such housing in the future.

3. ***Congress should direct the Department of Housing and Urban Development that programs to provide rent subsidies for persons with disabilities through both Section 8 certificates and the housing voucher program should be made permanent and given a high priority.***

The Administration-endorsed voucher program, initiated as a demonstration project, has proven to be an effective vehicle for providing persons with disabilities the opportunity to select their own places of residence. In addition, the traditional Section 8 certificate program continues to serve an important purpose in assisting disabled people by providing rent subsidies. The Section 8 New Construction program is a major financial incentive for developers to construct Section 202 housing for disabled persons. Twenty percent of all Section 8 certificates should be set aside for persons with disabilities. HUD should clarify maximum rent criteria under Section 8 to uniformly permit persons with disabilities to share apartments with others. Income eligibility criteria for Section 8 certificates and vouchers should be based upon actual net income of applicants with disabilities after the deduction of disability-related expenses.

4. ***Congress should direct the Department of Housing and Urban Development to reorganize the Section 202 program to provide a range of housing options for persons with disabilities, and to include a program of demonstration grants to agencies such as Independent Living Centers to develop model housing options, including transitional living programs, group residences, and other alternatives.***

The Administration has recognized that private production may not be sufficient to meet the housing needs of elderly people and persons with disabilities (HUD, 1984, p. 61). Consequently, Section 202 or a similar Federally funded program is needed to stimulate the construction of additional housing units for people with disabilities. The traditional Section 202

program, however, has engendered certain problems, such as isolation of people with disabilities, and lack of age-appropriate social integration. As HUD is reconsidering the structure and goals of the Section 202 Program during the current moratorium on Section 202 construction, the program should be reorganized to provide several different types of housing options for people with disabilities. These would include group homes and other disability-specific residential programs for persons needing supervised supportive living environments, as well as integrated housing in the community for the majority of persons with disabilities who do not need such supervised support.

All housing constructed under such a program should meet general standards of accessibility, as discussed in Recommendation 2 above. The developer/management of such a project should be required to provide tenants with disabilities the option of being interspersed with nondisabled tenants. Tenants with disabilities should also be integrated with other tenants on an age-appropriate basis.

A HUD program should be established to initiate demonstration projects to provide funds to agencies such as Independent Living Centers to develop model housing options for future HUD construction funding. Such housing alternatives, including transitional living programs, group residences, and other arrangements, will provide alternative models to the traditional Section 202 high-rise apartment buildings, and stimulate more appropriate housing opportunities for citizens with disabilities and elderly persons.

These recommendations do not necessarily contemplate any increase in funding of the Section 202 Program, but rather a reallocation of the use made of Section 202 funds at current spending levels.

5. ***Offices responsible for disability issues should be established within HUD's Fair Housing and Equal Opportunity Division and within the Office of Policy Development and Research.***

These two offices would provide much needed administrative focus on disability-related issues within the Department. The former would serve to guide the enforcement of Section 504 and other legal and regulatory requirements, while the latter would provide important input to HUD disability policy direction.

6. ***Congress should direct HUD to issue appropriate regulations for the implementation of Section 504 of the Rehabilitation Act of 1973.***

A timeline should be imposed for the issuance of Section 504 housing regulations. HUD should be directed to involve disabled individuals, the National Council on the Handicapped, and disability organizations in the process of developing and issuing such regulations. Such regulations should not permit the imposition upon housing applicants with disabilities of any standards or criteria, such as neighbor attitudes or apartment maintenance, unless such criteria are necessary, nondiscriminatory, and are

imposed upon all tenants. HUD's regulations should provide that recipients of HUD funds are prohibited from unintentional as well as intentional discrimination on the basis of handicap. Recipients should be required to assure that practices, procedures, and facilities do not inadvertently exclude or disadvantage tenants or potential tenants with disabilities. The regulations should also require compliance with accessibility requirements as set out in Recommendation 2 above.

7. Additional programs should be initiated to leverage existing private sector funding and to provide incentives and financial resources for the development of housing opportunities for people with disabilities.

FHA and other governmental and private housing loan funds should be equally available to persons with disabilities. Federal housing loan programs whose eligibility criteria include income-level ceilings should reflect actual net income after the deduction of disability-related expenses.

Rather than focusing on making and administering housing loans, HUD should be authorized to "buy down" interest rates on loans offered and administered by private financial institutions. Other incentive programs should include:

a. *Expanding the existing Federal income tax deduction for the removal of architectural barriers, including increasing the amount eligible for deduction;*

b. *Instituting low-interest loans or loan guarantee programs to provide people with disabilities who are eligible for rent subsidies the option of purchasing a comparable home, thus reducing the long-term need for rent subsidies; and*

c. *Establishing low-interest loan programs or tax incentives to encourage private sector construction of single-family housing, cooperatives, and condominiums for individuals with disabilities.*

These proposals reflect the fact that the average annual per unit expenditure for rent subsidies in 1985 amounted to $6,459 in Section 202 facilities; $4,659 under Section 8 existing certificates; and $3,404 under the voucher system. Such amounts of money could be used to provide interest subsidies that would enable eligible individuals with disabilities to purchase homes at low interest rates, and to eventually cease needing any housing subsidy.

8. ***HUD and the private sector should be encouraged to develop training grants, supplemental teaching positions, awards, and other innovative programs for promoting architectural planning that incorporates the concept of universal accessibility.***

Aspiring architects and planners should be provided the training necessary to enable them to develop innovative designs implementing universal accessibility in new and rehabilitative construction. Such innovations may dramatically transform the design and construction of housing, public and private buildings, schools, work places, and public transit systems, and eliminate environmental barriers to elderly persons and people with disabilities.

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Community-Based Services for Independent Living

The Council has defined independent living as "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities" (National Policy for Persons with Disabilities, 1983). Living independently includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles including productive work, and making decisions that lead to self-determination. Community-based services that promote such independence for Americans with disabilities constitute one of the most promising service delivery strategies for our Nation.

The Council wishes to affirm that the independent living philosophy and a preference for community-based services should permeate the services and benefits supported by the Federal Government. The goal should be to establish core funding for a continuum of community-based services guided by independent living concepts.

In order to live independently, disabled persons require a wide range of support services according to their disability type. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities may require assistance with interpersonal communication such as that provided by readers and interpreters. Persons with mental impairments who wish to live independently may require some degree of supervision and assistance with cognitive tasks. All persons with disabilities and their families can benefit from a single source of information and referral about services and service providers.

In 1978, Congress incorporated a program of Comprehensive Services for Independent Living in Title VII of the Rehabilitation Act. It was the first Federal legislation to specifically authorize funding for services needed by people with such severe disabilities that they do not presently have the potential for employment. It permits services to be provided to those presently without employment potential if they may benefit from vocational rehabilitation services (authorized under Title I, Part A) which will improve their ability to engage in employment or to live and function independently in their families or communities. Part A of Title VII authorizes payments for independent living services that are provided under approved State plans. Part B authorizes a grant program for the establishment and operation of independent living centers that offer, among other services, the services funded under Part A. Part C authorizes funds to provide independent living services for elderly blind individuals.

Funding for independent living services under Title VII is very limited when compared to Medicaid (Title XIX of the Social Security Act) funding for institutional care for people with severe disabilities. If community-based independent living is to become a realistic goal for Americans with severe disabilities, institutional bias within Medicaid and other programs

funded under the Social Security Act must be replaced by a preference for community-based services.

Recommendations

1. ***Congress should require the agency in each State designated to administer Title VII, Part A of the Rehabilitation Act to allocate no less than 50% of available funds to purchase services from independent living centers that meet the standards approved by the National Council on the Handicapped. No more than 10% of available funds should be used for administrative purposes. The remaining funds should be used at the discretion of the administering agency in any way that assists people with severe disabilities to achieve independence and productivity in their communities.***

Currently States are required to provide assurances in their State Plans that no less than 20% of the funds received by a State under Part A are used to make grants to local public agencies and private nonprofit organizations for the conduct of independent living services (unless a waiver of this requirement is obtained from the Commissioner of the Rehabilitation Services Administration). The Council recommends that this percentage be increased to 50% to assure that funding for independent living services is available to and provided by agencies established and operated for this purpose under Title VII, Part B. Such funding for services should be authorized only for independent living centers that comply with the standards approved by the Council.

Coordinated services are essential to the ability of a person with a severe disability to live in the community. Therefore, the Council recommends that States applying for Part A funds be required to submit a plan for the coordinated delivery of services, including personal assistance services (attendants, readers, interpreters, and advocates for mentally retarded persons); and accessible housing and transportation; and for State-wide information and referral services for all people with disabilities and their families. Administrative expenses for arranging services should be strictly limited to 10% of these funds.

The Council recommends that funding for Part A be continued as a means of ensuring that community-based services are made available to persons with severe disabilities. Its implementation should include requirements that independent living facilities and services comply with standards approved by the Council for program administration, service delivery, and program evaluation.

2. ***Congress should provide core funding under Title VII, Part B of the Rehabilitation Act, for independent living centers that meet the standards approved by the National Council on the Handicapped. Such centers should be allowed to apply and compete for this funding on an equal basis with State vocational rehabilitation agencies.***

Community-based, consumer-controlled independent living centers were created to assist persons with severe disabilities to increase their level of

independence. As defined in Title VII, Part B of the Rehabilitation Act, these centers must significantly involve disabled persons in policy direction and management, and must offer a combination of independent living services. Part B of Title VII, which funds over 150 of these centers nationwide, should be used as an ongoing source of funding to support the start-up of new centers and to provide core support for established centers, whether or not these centers have received Title VII funding in the past. At least 20% of Part B funds should be used to support the establishment of new independent living programs, with an emphasis on rural and other underserved areas. The remaining available funds should be used for core support of established centers.

The standards adopted by the National Council in 1985 for evaluating independent living centers should be enforced as a prerequisite for the distribution of funds. New centers which do not meet the standards at the time they apply for Federal funding should be required to follow a pre-application process and have a plan to meet the standards before receiving Federal funding. In addition, independent living centers should be strongly encouraged to obtain funding from other public and private sources. All centers should include representatives of the business community on their boards of directors. A mechanism should be established to provide incentives for States to match Federal efforts for independent living centers.

The Council wishes to note that in requiring independent living centers to be consumer-controlled, it defines "consumer" as including persons with all types of disabilities. It believes that those with mental retardation or a history of mental illness, for example, can serve a vital role as consumer members on boards or in other responsible positions.

3. ***Congress should require the Health Care Financing Administration to study the institutional bias within its programs for persons with disabilities and to develop appropriate measures for eliminating such biases. The criteria should be developed in consultation with the National Council on the Handicapped and be reported in hearings before Congress within one year from the date of enactment of this requirement.***

An extraordinary amount of the Medicaid funds administered by the Health Care Financing Administration (HCFA) is spent on nursing homes and other long-term institutions that primarily provide custodial maintenance for disabled individuals. The Council believes that strictly maintenance-oriented institutional programming is indefensible and unnecessary. Wherever possible, institutions should be transitional and foster independence. The majority of available funding should be directed toward assisting all individuals with severe disabilities to achieve self-direction and independence to the maximum of their potential, in the most dignified and least restrictive environment.

The Council recommends that Congress require the HCFA to develop, posthaste, in consultation with the National Council on the Handicapped, criteria to be used to determine to what extent Medicaid and other programs administered by HCFA promote community-based services and discourage placements in institutions. Programs that serve people with disabilities should be assessed using these criteria, and the resulting report should be used as a basis for making fundamental changes in the management and structure of these programs. The Council recommends that the Congress hold hearings within one year of the enactment of this requirement to review HCFA findings and plans for action.

The evaluation criteria should include a focus on the following topics:

- Comprehensive personal assistant services, including long-term, short-term (respite), and emergency attendants, readers, interpreters, and advocates for mentally retarded people.
- Case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community; and assistance in equipment selection and maintenance, and in locating sources for other independent living support services.
- Family support and consumer education services, including financial and personal counseling and training in self-directed and family-provided home care, including the use of equipment and medication, and independent living skills training.
- Habilitative and rehabilitative training, including prevocational services.
- Comprehensive medical insurance for disabled persons who are unable to obtain adequate insurance through their employers or who are ineligible for other Federal medical benefits.

4. Congress should amend the Internal Revenue Code to establish a tax credit for taxpayers with disabilities who incur unreimbursed expenses directly related to independent living, employment, and efforts to secure employment, including personal assistant services, special transportation, assistive devices, and other support services.

This recommendation is made as a partial means of removing the disincentives to work which are inherent in the Social Security system. While certain tax deductions are currently allowable under a medical categorization, the regulations are unclear regarding non-medical, disability-related services which enable the individual to work or engage in productive activity. Such expenses, up to a reasonable amount for each type of expense, should be made deductible.

Educating Children With Disabilities

Special education helps this Nation's children with disabilities to develop the skills they need to live as independently as possible when they become adults. Although special education services have progressed greatly since the passage of the Education for All Handicapped Children Act over ten years ago, the knowledge and ability to implement "best practices" falls short of what is needed.

First and foremost, there is a need to encourage the States to make available special education and related services beginning at birth. Of an estimated 250,000 children under the age of two who could use special education services each year, only 60,000 receive services. Just seven States mandate that special education services should be provided to infants. In addition, the availability and quality of services for young children with special needs varies greatly from State to State.

Educational services for infants are typically provided in the home, with educators and parents working together closely to enhance the child's educational development. Considerable evidence, summarized in the Council's detailed topic paper on "Educating Children with Disabilities" (in the separate Appendix to this report), indicates that early intervention programs that actively involve parents result in greater ultimate educational achievement, improve the quality of life of disabled children and their families, and reduce the extent of need and therefore the cost of special education services in later years. As a result, early intervention services produce considerable tax savings over the long run.

A second critical issue is the need to educate children with special needs in regular education settings. Students of all ages and ability levels who are placed in non-restrictive environments can learn the skills and behaviors needed to fully participate in society as contributing adults. This does not mean placing students in the nearest school irrespective of individual needs and abilities, nor does it mean placing students with disabilities into regular classrooms when they need special services. In most cases, a free appropriate public education should be provided to children with disabilities in age-appropriate regular school buildings that offer special education and related services. The Council recognizes that there are situations in which a child's educational needs require placement in an appropriate private school setting or in a specialized public school program. Academic programs must be tailored to meet individual needs while allowing time for disabled and nondisabled peers to be together all or part of each day.

With technical assistance and careful planning, local school districts and parents can establish totally integrated educational programs that are appropriate to a range of needs. School districts in Albuquerque, New Mexico; Madison, Wisconsin; San Francisco, California; and Birmingham, Alabama all have major integration programs that appropriately meet the needs of all children, including those with the most severe handicaps.

A third issue centers on the need to conduct a national assessment of the status of special education today. The National Commission on Excellence in Education and similar studies have not addressed special education. There is a serious need for a high-level, in-depth study of trends, issues, and problems affecting the Nation's system of special education.

Recommendations

1. ***Congress should amend the Education for All Handicapped Children Act to encourage States to make available a free appropriate public education to every disabled child from birth through age twenty-one.***

To effectively serve children with disabilities, equal educational opportunity under Public Law 94-142, as amended, should be extended to all children beginning at birth. A report by the staffs of Congressmen Coats and Miller stated that very early intervention services which benefit children and their parents result in significant tax savings in the long run because of reduced special education expenditures in later years.

The proposed amendments should include the following provisions: a) each State education agency should be the lead and coordinating agency for the services; b) an early childhood specialist should be appointed in each State to ensure that the services are properly planned and implemented; c) Public Law 89-313 funds should follow the child from State institution services to pay for needed community-based services; d) each State education agency and State Medicaid agency should develop interagency agreements that list early intervention services (except for the costs of the educator) as Medicaid reimburseable items; and e) States should develop other appropriate funding mechanisms to meet their individual needs.

2. ***Congress should direct the Department of Education to promulgate and enforce standards for the application of the least restrictive environment requirement; such standards should clarify that the primary determinant of which educational setting is least restrictive is the educational appropriateness of the program.***

The least restrictive environment mandate is a major component of the right to a free appropriate public education for children with disabilities. The principle has not, however, always been appropriately applied by State and local education agencies. In some instances, least restrictive environment has been used as a rationale for educational programs that are more "mainstream" than the educational needs of a particular student dictate. In other instances, the least restrictive environment has not been vigorously applied and children with disabilities continue to be unnecessarily segregated. The Department of Education should provide more direct guidance to education agencies by issuing standards for the application of least restrictive environment principle. Such standards should focus upon educational appropriateness as the critical factor in determining what is the least restrictive program for a particular child. Determining educational appropriateness, in turn, should incorporate a presumption against unnecessary social isolation of children with disabilities.

3. ***Congress should direct the Office of Special Education Programs to fund a national technical assistance center to help parents and State and local education agencies plan and develop educational options for children with special needs.***

To help State and local education agencies and parents appropriately plan for and meet the range of needs of students with disabilities, a national technical assistance center should be funded. This center would provide the staff, materials, and other resources required to help the 57 State and territorial education agencies train parents, teachers, students, and administrators to develop age-appropriate programs for students with disabilities. Materials and information developed by the national technical assistance center would be available for dissemination by the network of special education regional resource centers already in place.

4. ***Congress should direct the Secretary of Education and the Chairperson of the National Council on the Handicapped to establish a National Commission for the Study of Excellence in Special Education.***

Public Law 94-142, as amended, was enacted more than ten years ago. Its enactment has resulted in major changes in the provision of special education services in this country. A special commission should be established to assess what has been achieved and to determine the most cost-effective methods of fully achieving the goals of special education in the future. The Secretary of Education and the Chairperson of the National Council on the Handicapped should each appoint an equal number of members to the commission. The commission should be asked to report its findings and recommendations to Congress within two years of the enactment of this provision.

Personal Assistance: Attendant Services, Readers, and Interpreters

In reviewing the types of programs funded by the Federal Government, the Council has found that there is an undue reliance on institutional care. The Council believes that personal assistance, as rendered by attendants, readers, interpreters, and advocates, when provided in conjunction with other community-based services, can be an effective and economical means for reducing this Nation's reliance on institutions and enabling most persons with disabilities to live independently in settings of their choice. The goal should be to establish self-directed personal assistant services as one component of a comprehensive array of community-based services that should be available to people with disabilities.

People with severe disabilities have a long-term need for support services. Stable funding and a coordinated system for providing personal services are needed if our society is to develop effective community-based alternatives to institutional care. The Council believes that the following recommendations are essential first steps in reaching this goal.

Recommendations

1. Congress should establish a national policy that defines personal assistance and should require the development of national standards for the delivery of personal assistance services.

A national personal assistance policy should be developed to assure that programs offering personal assistance are required to:

- Serve people with all types of disabilities on the basis of functional need,
- Serve people of all ages,
- Provide for the optimum degree of self-direction and self-reliance as appropriate for individual consumers,
- Be accessible to people at all income and asset levels with cost sharing as appropriate,
- Include assistance with personal, cognitive, communicative, domestic, and other related services,
- Include 24 hour, 7 day a week service, short-term (respite), and emergency assistance as needed,
- Be available where needed (e.g., home, work, school, recreation, travel),
- Not create disincentives to employment,
- Offer the consumer a range of employer/employee and contract agency relationships,
- Provide for outreach and training of consumers as needed,
- Provide for training of administrators and staff of provider organizations with an emphasis on preparing organizations directed and staffed primarily by persons with disabilities to provide personal services,

- Provide for reasonable wages and basic benefits for personal assistants, readers, and interpreters, and,
- Require significant participation of consumers in program policy determination and administration.

The development of a coordinated, effective approach to the delivery of personal assistant services requires that a comprehensive definition of these services be incorporated into the Social Security Act, the Rehabilitation Act of 1973, the Education for All Handicapped Children Act (P.L. 94-142), the Developmental Disabilities Act, the Older Americans Act, and Veterans benefits legislation. This definition should be a product of discussions between representatives of major disability groups.

A national policy-making body should set standards, subject to the review and approval of the Council, for the expenditure of personal assistant service funds to assure that these services are self-directed and responsive to the varied needs of disabled persons and their families.

2. ***Congress should require the Social Security Administration (SSA), in consultation with the National Council on the Handicapped, to implement a series of projects, using SSA demonstration authority and targeting currently available funds, to develop and demonstrate a cost-effective process and mechanisms for the support of community-based personal assistant services for persons with severe disabilities.***

The rechanneling of some of the funds that support institutions to support the development of consumer-directed, community-based systems for the delivery of personal assistant services, as rendered by attendants, readers, and interpreters, is a challenging task. It will require careful preparation and step-by-step implementation. The Council believes that a series of demonstration projects would be a productive approach to developing a cost-effective national system of personal assistant services.

A major portion of the resources which support persons with severe disabilities in institutional settings comes from Title XIX of the Social Security Act. While other provisions of this Act enable people with disabilities to receive a variety of social services and income support benefits, strict eligibility requirements regarding income and the involvement of medical professionals in the delivery of services hinder the ability of disabled people to live independently. For a substantial portion of these individuals, lives of considerably more independence and productivity would be possible if funding currently consumed by institutions and services requiring medical supervision could be made available for personal assistant services.

Changes in the language in specific titles of the Social Security Act could have far-reaching economic implications. Such changes should be preceded by comprehensive studies of the most cost-effective methods for increasing funding for personal assistant services and ensuring that

the guidelines for a national personal assistance system are upheld. These studies should significantly involve the input of persons with disabilities in all phases, including planning and evaluation.

The recommended projects should be funded under the demonstration authority of the Social Security Administration using currently available funds. While funded by SSA, such projects should address the needs of persons who do not qualify for Social Security benefits as well as those who do. Such projects should:

a. *Determine the extent of the national need for personal assistance,*

b. *Determine the cost of providing services to meet that need,*

c. *Determine the efficacy of personal assistant services models,*

d. *Determine the cost-effectiveness of a national personal assistance service plan,*

e. *Determine the feasibility of implementing a national personal assistance service plan, and*

f. *Determine the ultimate implications for the Federal budget by evaluating potential savings through reduced institutional costs and enhanced income from increased taxes as personal assistance services enable severely disabled persons to become employed or to live outside of institutions.*

These demonstration projects should be carefully designed and evaluated since they would help establish the parameters of a national attendant services program.

Coordination

As Federal programs seek to promote independence and equal opportunities for people with disabilities, there is an important need that services and programs be coordinated. "Coordinated services" describes the ideal results of a wide range of interactions among persons active in policy and program development. Although these interactions take place every day, their purpose, frequency, and effectiveness vary greatly from community to community, State to State, and from program to program. In the Forums conducted in 1984 and 1985 as part of the Council's background activities leading to this report, disabled people around the country declared that many programs do not mesh well with other available services, and that too often the service delivery system exhibits gaps, inconsistencies, and inequities. It is clear, however, that there is no single or simple solution to the need for better coordinated services. The Council believes that mechanisms should be in place throughout the service delivery system that consistently and purposefully attempt to improve the linkages among the policy makers and programs that serve disabled people.

The Council advocates frequent and purposeful interaction at the national level of all parties involved in policy decisions that affect services to people with disabilities. To that end, the Council pledges to maintain its information base with consumer organizations around the country while strengthening interaction on coordination issues with State, local and national policy actors, private organizations, the Congress, and the Administration. This process will continually identify coordination issues which can best be resolved through specific legislative or administrative actions. In addition to these national level activities, state and local planning by recipients of Federal funding should be fostered in every community.

Recommendations

1. ***Congress should require State and local agencies that receive Federal funds for services for people with disabilities to participate in the development of coordinated service delivery plans.***

A State planning requirement is in place for citizens with developmental disabilities. The Council recommends that a similar planning process should address the needs of all citizens with disabilities and that it should occur at the local as well as the State level. The planning process should seek the involvement and participation of existing planning mechanisms in each State and community. For this reason, lead agency responsibility and a detailed schedule for the creation of such plans should be assigned by the appropriate governor or mayor.

At a minimum, State and local agencies that receive or administer Federal funds for the following benefits and services should participate in the planning process: Veterans benefits and services; Social Security Disability Insurance, health services, long-term care and medical insurance programs; education; mental health, mental retardation, rehabilitation and independent living services; Title XX; Worker's Compensation; employment and training (Job Training Partnership Act); housing and transportation; developmental disabilities planning and services.

In addition, the process should, by requirement and design, substantively involve people with disabilities in the planning process. The planning process should specifically address methods of improving service delivery. Particular attention should be paid to the needs of individuals with disabilities who do not fit neatly into established service categories. For instance, careful planning should prevent persons with disabilities who are declared ineligible for SSDI from being denied vocational rehabilitation services. It should assure that appropriate services are delivered to people with multiple handicaps, such as the estimated 15-20% of mentally retarded individuals who also have emotional problems. In States and local communities, the planning process should lead to improved communications, more integrated services, and better informed policy discussion. No additional Federal costs are associated with this recommendation; if implemented in good faith at the State and local levels, the planning process should lead to improved services at equal or reduced costs. Such cooperative planning will help to engender a Federal, State, local, and private sector partnership in rendering effective and nonduplicative services to enhance the opportunities for equality and independence for persons with disabilities.

List of Federal Programs Affecting Persons With Disabilities in Order of Expenditure

Federal programs directly benefiting disabled persons are listed below in descending order of program size. Program size was determined by review of the 1986 estimates for each program as presented in the 1985 Catalog of Federal Domestic Assistance. If significant differences were reflected between 1985 estimates and 1986 estimates as presented in the 1985 CFDA, additional references were sought and noted accordingly.

Programs included on the list are those for which spending on disabled persons could be identified or reasonably estimated and/or rationalized.

Programs were not included if:

a. They were small in dollars (usually less than one million dollars).
b. They provided funding only for administrative or enforcement action.
c. They primarily served to train professionals rather than disabled persons.
d. They were not administered by an Executive Branch Agency (i.e., Gallaudet, NTID).

There are several large programs which were not included on the list because the specific amount of monies spent on disabled persons cannot be determined nor can the actual number of disabled persons served by the program be determined. These programs include:

a. Alcohol, Drug Abuse and Mental Health Services Block Grants
b. Food Stamps
c. Title XX Social Services Block Grants
d. Maternal and Child Health

A forthcoming recommendation of the National Council on the Handicapped will be that agencies administering such programs develop and implement methods for monitoring their respective programs relative to their impact on persons with disabilities.

Four programs were included on the list because they reflect Federal efforts on behalf of policy setting and advisory functions as well as standard setting and enforcement functions. These programs are:

a. President's Committee on Employment of the Handicapped
b. Architectural and Transportation Barriers Compliance Board
c. President's Committee on Mental Retardation
d. National Council on the Handicapped

For purposes of this listing, disabled persons includes both disabled and blind recipients combined for those programs which list each separately.

Spending totals and beneficiaries are estimates for disabled persons only.

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1. SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Authorization:	42 U.S.C. 420–425
CFDA:	13.802
Agency:	Social Security Administration
FY 1986 Est.:	$19,566,567,000
Disabled Persons Benefiting:	3,900,000

The SSDI program is intended to replace part of the earnings lost because of a physical or mental impairment severe enough to prevent a person from working. It serves about 2.8 million disabled persons and 1.1 million dependents. All disabled recipients are under 65 years of age. Monthly cash payments range to a maximum of $909 for an individual and $1,364 for an individual with eligible dependents. The average monthly benefit in January 1985 was $454 for an individual and $885 for an individual with dependents. [CFDA, Social Security Bulletin]

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2. MEDICARE

Authorization:	42 U.S.C. 1395 et seq. 42 U.S.C. 1305 Note
CFDA:	13.773 (Hospital Insurance) 13.774 (Supplementary Insurance)
Agency:	Health Care Financing Administration
FY 1986 Est.:	$9,000,000,000
Disabled Persons Benefiting:	2,750,000

The Medicare program provides hospital and medical insurance protection for disabled individuals under 65 years of age who have qualified for SSDI coverage for 24 months or for railroad retirement benefits based on disability for 29 consecutive months; in addition, many under-65 persons with chronic kidney disease are eligible. Disabled beneficiaries represent about 9% of the estimated 30,870,000 persons receiving Medicare assistance. Medicare spending on disabled persons comprises about 13.5% of the $75 billion annual Federal outlays on both parts of Medicare. [CFDA; Social Security Bulletin; Rutgers Univ.; Committee on Ways & Means, 2/22/85, page 123]

3. MEDICAID

Authorization:	42 U.S.C. 1396 et seq.
CFDA:	13.714
Agency:	Health Care Financing Administration
FY 1986 Est.:	$8,820,000,000
Disabled Persons Benefiting:	3,150,000

Medicaid is a means-tested assistance to states program for persons who are poor. Disabled individuals may qualify if they demonstrate eligibility for Supplemental Security Income (SSI). Disabled beneficiaries represent about 14% of the 22,500,000 persons receiving Medicaid. Spending on these persons accounts for approximately 36% of the $24,500,000,000 spent by the Federal government on Medicaid. [CFDA, Social Security Bulletin, Rutgers Univ.]

4. VETERANS COMPENSATION FOR SERVICE-CONNECTED DISABILITIES

Authorization:	38 U.S.C. 310,331
CFDA:	64.109
Agency:	Veterans Administration
FY 1986 Est.:	$8,210,732,000
Disabled Persons Benefiting:	2,220,000

This veterans' compensation program provides direct payments to veterans having service-connected disabilities, to a maximum of $3,697/month. All recipients are disabled. [CFDA]

5. SUPPLEMENTAL SECURITY INCOME (SSI)

Authorization:	42 U.S.C. 1381-1383c
CFDA:	13.807
Agency:	Social Security Administration
FY 1986 Est.:	$6,400,000,000
Disabled Persons Benefiting:	1,927,000

SSI provides a minimum guaranteed income for under-65 disabled individuals who meet a means test and who are unable to engage in substantial gainful activity. Monthly payments range to a maximum of $325; $488 for an eligible person with a spouse. The average monthly benefit in 1984 was $186; the average monthly payment in 1986 is estimated to be $199. Disabled beneficiaries represent about 47% of the 4,100,000 persons receiving payments. Benefits paid to disabled recipients comprise approximately 70% of the $9,200,000 FY 1986 estimated Federal outlays for SSI. Many states provide supplementary benefits. [CFDA; Rutgers Univ.; Office of Supplemental Security Income, SSA, Interview, Michael Staren, Dec., 1985]

6. PENSION FOR NON-SERVICE CONNECTED DISABILITIES

Authorization:	38 U.S.C. 511,512,521
CFDA:	64.104
Agency:	Veterans Administration
FY 1985 Est.:	$2,550,000,000
Disabled Persons Benefiting:	676,000

This program provides an annual pension of approximately $5,700, reduced by countable income, for an individual; $4,780 for a veteran with one dependent; and $968 for each additional dependent. If the veteran is in need of personal attendant care, the pension may increase to $9,132 for an individual and $10,902 for a veteran with one dependent. All participants are disabled and are veterans of wartime service. [CFDA]

7. EDUCATION OF HANDICAPPED CHILDREN

Authorization:	20 U.S.C. 1401–1419
CFDA:	84.027
Agency:	Department of Education
FY 1986 Est.:	$1,164,000,000
Disabled Persons Benefiting:	4,200,000

This program provides grants to states to assist them in providing a "free, appropriate, public education" for handicapped children, including preschool students. The per-student payment by the Federal Government averages about $265; the Federal share of each $16 spent in special education is $1. All program participants are disabled. [CFDA, Dept. of Education]

8. VOCATIONAL REHABILITATION

Authorization:	29 U.S.C. 701
CFDA:	84.126
Agency:	Department of Education
FY 1986 Est.:	$1,100,000,000
Disabled Persons Benefiting:	931,800 (1985 est.)

This program provides grants to states to enable them to deliver counseling and related services to disabled persons. Approximately 226,000 persons are "rehabilitated" to gainful employment annually. The Federal outlay per person served per year is about $1,200. The Federal share of each dollar spent on rehabilitation is about eighty cents. [CFDA, Dept. of Education]

9. SPECIAL BENEFITS FOR DISABLED COAL MINERS

Authorization:	30 U.S.C. 901–945
CFDA:	13.806
Agency:	Social Security Administration
FY 1986 Est.:	$979,000,000
Disabled Persons Benefiting:	300,000

This "black lung" program makes direct payments to coal miners who become disabled with pneumoconiosis or other chronic lung disease and to their widows. No new applications have been accepted since 1973, except for survivors' benefits. The basic monthly payment is $328, with a maximum of $656 as of January 1985. All beneficiaries are disabled. [CFDA]

10. SOCIAL INSURANCE FOR RAILROAD WORKERS

Authorization:	45 U.S.C. 351–367; 45 U.S.C. 231–231u
CFDA:	57.001
Agency:	Railroad Retirement Board
FY 1986 Est.:	$775,000,000
Disabled Persons Benefiting:	104,500

This insurance program includes disability benefits for railroad workers who retire due to disability or who are sick or injured and unable to work and for their dependents, pursuant to the Railroad Retirement Act

and the Railroad Unemployment Insurance Act. The maximum monthly benefit for disabled retired beneficiaries is about $1,283, with the average being $612; for disabled unemployed and sick workers, the maximum is $500 per month and the average also is $500 per month. Payments to disabled persons comprised about 12.5% of the program's $6,200,000,000 outlays for FY 1986. Approximately 11% of the program's 950,000 beneficiaries are disabled. [CFDA; Marla Huddlston, staff, Railroad Retirement Board, interview, December, 1985]

11. COAL MINE WORKERS COMPENSATION

Authorization:	PL 97-119
CFDA:	17.307
Agency:	Department of Labor
FY 1986 Est.:	$632,868,000
Disabled Persons Benefiting:	190,200

Direct payments are made to coal miners disabled by black lung disease and their dependents. The basic monthly rate is $328, with a maximum for the claimant with three dependents being $656. The average as of January 1985 was $415 per month exclusive of medical benefits for treatment of black lung disease. All beneficiaries are disabled. [CFDA]

12. LOWER INCOME HOUSING ASSISTANCE (SECTION 8)

Authorization:	42 U.S.C. 1401-1435, 1437
CFDA:	14.156
Agency:	Department of Housing and Urban Development
FY 1986 Est.:	$400,000,000
Disabled Persons Benefiting:	100,000

Section 8 rent subsidies are paid to building owners to help defray rental costs; the beneficiaries pay 30% of adjusted income for rent. Disabled beneficiaries are estimated at about 5% of the program's $8,000,000,000 outlays. [CFDA, Social Security Bulletin, Rutgers Univ.]

13. EDUCATION OF HANDICAPPED CHILDREN IN STATE-OPERATED OR -SUPPORTED SCHOOLS

Authorization:	PL 98-211
CFDA:	84.009
Agency:	Department of Education
FY 1986 Est.:	$150,170,000
Disabled Persons Benefiting:	247,000

This program helps states to improve services for handicapped students in state-operated or -supported schools and institutions. Handicapped children through age 20 whose education is the state's responsibility may be served. The average per-student Federal payment is about $592/year. [CFDA, Dept. of Education]

14. VOCATIONAL REHABILITATION FOR DISABLED VETERANS

Authorization:	38 U.S C. 1502
CFDA:	64.116
Agency:	Veterans Administration
FY 1986 Est.:	$116,000,000
Disabled Persons Benefiting:	35,000

This program provides payment for education expenses, including full tuition, books, and fees and supplies, as well as monthly allowances. The monthly payment ranges to a maximum of $310 for a single veteran and $452 for a veteran with two dependents. Non-interest-bearing loans are also available, for up to $620 per enrollment period. In FY 1986, an estimated 28,400 trainees will be helped and some 6,495 veterans will receive loans. All recipients are disabled or hospitalized. [CFDA]

15. VETERANS PROSTHETIC APPLIANCES

Authorization:	38 U.S.C. 362 et al.
CFDA:	64.013
Agency:	Veterans Administration
FY 1986 Est.:	$100,869,000
Disabled Persons Benefiting:	1,000,000

This program purchases aids and devices for disabled veterans. Medical equipment, hearing aids, orthopedic shoes, prosthetic devices and other appliances are provided. The range of purchase and/or repair expenditures is from about $10 to $25,000, with an average per aid of $67. In FY 1986, the VA expects to purchase or repair some two million aids. [CFDA]

16. HOUSING FOR THE ELDERLY OR HANDICAPPED (SECTION 202)

Authorization:	12 U.S.C. 1701q; 73 Stat. 654, 667
CFDA:	14.157
Agency:	Department of Housing and Urban Development
FY 1986 Est.:	$110,000,000
Disabled Persons Benefiting:	Information Unavailable

The HUD section 202 program allocated some $109 million of $557 million in FY 1985 in direct loans for construction of 2,700 units for handicapped persons. Residents also received section 8 rental assistance. The section 202 program has $631 million available in FY 86. [CFDA, ARC-US]

17. VOCATIONAL EDUCATION—BASIC GRANTS TO STATES

Authorization:	20 U.S.C. 2331-2342
CFDA:	84.048
Agency:	Department of Education
FY 1986 Est.:	$72,000,000
Disabled Persons Benefiting:	490,000

This program, most recently reauthorized by Carl D. Perkins Vocational Education Act, offers vocational education to handicapped students, most at the secondary level. Estimated Federal expenditures on the Perkins program for FY 1986 are $723,141,000. About 490,000 of the 13,000,000 students assisted are handicapped. Of these persons, 290,000 are served using the mandatory 10% setaside of Federal funds while 200,000 are mainstreamed into ongoing vocational education programs at no extra cost to the Federal Government. Enrollment by handicapped students benefiting from the 10% setaside in vocational education programs represents 3% of all students in these programs. [CFDA]

18. DEVELOPMENTAL DISABILITIES—BASIC SUPPORT AND ADVOCACY

Authorization:	PL 98-527
CFDA:	13.630
Agency:	Department of Health and Human Services
FY 1986 Est.:	$64,000,000
Disabled Persons Benefiting:	Information Unavailable

This program assists states to provide cross-cutting services and protection-and-advocacy assistance to persons with severe disabilities occurring prior to age 22. All beneficiaries are disabled. Most funds are used for advocacy activities benefiting numerous persons, rather than for direct services. [CFDA]

19. NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

Authorization:	PL 98-221
CFDA:	84.133
Agency:	Department of Education
FY 1986 Est.:	$39,000,000
Disabled Persons Benefiting:	Information Unavailable

NIHR conducts research and demonstration projects and programs and disseminates research findings. Most funds are allocated to research/training or rehabilitation engineering centers. [CFDA]

20. BOOKS FOR THE BLIND AND PHYSICALLY HANDICAPPED

Authorization:	2 U.S.C. 135
CFDA:	42.001
Agency:	Library of Congress
FY 1986 Est.:	$38,402,000
Disabled Persons Benefiting:	630,000

This program provides books on cassette, disc and in Braille as well as machines to read them. A total of 56 regional and 102 subregional libraries are supported. [CFDA]

21. REHABILITATION SERVICES—SERVICE PROJECTS

Authorization:	29 U.S.C. 701
CFDA:	84.128
Agency:	Department of Education
FY 1986 Est.:	$29,300,000
Disabled Persons Benefiting:	Information Unavailable

This program provides demonstration grant monies to states and public nonprofit organizations to improve rehabilitation services to disabled persons. Funds provide for about 50 projects per year, of which about half are continuation grants from a prior year. [CFDA]

22. CENTERS FOR INDEPENDENT LIVING

Authorization:	29 U.S.C. 796e
CFDA:	84.132
Agency:	Department of Education
FY 1986 Est.:	$27,000,000
Disabled Persons Benefiting:	26,000

This program provides for grants to states or nonprofit organizations to establish and operate independent living centers serving severely disabled individuals. The average grant per 160 centers funded is about $175,000. Total includes $5 million for Part A independent living services. [CFDA, Dept. of Education]

23. URBAN MASS TRANSPORTATION CAPITAL IMPROVEMENT GRANTS

Authorization:	49 U.S.C. 1601 et seq.
CFDA:	20.500
Agency:	Department of Transportation
FY 1986 Est.:	$3,500,000
Disabled Persons Benefiting:	Information Unavailable

This program includes a 1% setaside of Federal gasoline tax revenues to be used to support transportation projects and programs benefiting disabled persons. Funding in FY 1985 for the entire program was about one billion dollars. For FY 1986 the Administration proposed a reduction to about thirty-five million; such a reduction would lower the 1% setaside drastically. [CFDA]

24. HANDICAPPED EARLY CHILDHOOD EDUCATION

Authorization:	20 U.S.C. 1423
CFDA:	84.024
Agency:	Department of Education
FY 1986 Est.:	$22,500,000
Disabled Persons Benefiting:	18,000 (1984 est.; FY 84 $21,000,000)

This program supports demonstration and dissemination projects for handicapped children below six years of age (in some cases, below eight years). About 170 projects are supported, many for parental training, and home-based instruction. [CFDA]

25. HANDICAPPED MEDIA SERVICES AND CAPTIONED FILMS

Authorization:	20 U.S.C. 1451-1453
CFDA:	84.026
Agency:	Department of Education
FY 1986 Est.:	$16,500,000
Disabled Persons Benefiting:	Information Unavailable

This program supports grants demonstrating innovative ways of using technology to assist disabled persons, captioning of films and of television programs, and training of teachers. [CFDA]

26. HANDICAPPED—INNOVATION AND DEVELOPMENT

Authorization:	20 U.S.C. 1441-1442
CFDA:	84.023
Agency:	Department of Education
FY 1986 Est.:	$16,000,000
Disabled Persons Benefiting:	Information Unavailable

This program supports research and demonstration projects to improve education for handicapped children and youth. Emphasis is upon model programs and instructional interventions. [CFDA]

27. DEAF-BLIND CENTERS

Authorization:	20 U.S.C. 1422
CFDA:	84.025
Agency:	Department of Education
FY 1986 Est.:	$12,000,000
Disabled Persons Benefiting:	6,100 (1984 est.; FY 84 $15,000,000)

This program serves some six thousand deaf-blind children and youth as well as 4,000 parents; 1,900 teachers; and 2,000 professionals who also work with deaf-blind persons. Grants, usually for one year, are offered to schools and other education agencies. [CFDA]

28. SPECIALLY ADAPTED HOUSING FOR DISABLED VETERANS

Authorization:	38 U.S.C. 801-806
CFDA:	64.106
Agency:	Veterans Administration
FY 1986 Est.:	$12,000,000
Disabled Persons Benefiting:	405 (84 est.; FY 84 $13,000,000)

This program provides up to 50% of the cost of housing, land, and other allowable expenses, to a maximum of $35,000, for disabled veterans and up to $6,000 for adaptations to the veteran's residence. [CFDA]

29. AUTOMOBILES AND ADAPTIVE EQUIPMENT FOR CERTAIN DISABLED VETERANS AND MEMBERS OF THE ARMED FORCES

Authorization:	39 U.S.C. Chapter 39
CFDA:	64.100
Agency:	Veterans Administration
FY 1986 Est.:	$12,000,000
Disabled Persons Benefiting:	650

This program provides financial assistance toward the purchase price of an automobile and additional funds for adaptive equipment such as lifts or hand controls. Service-connected disabilities affecting upper or lower limbs or producing blindness are covered. Up to $5,000 may be provided for an automobile or van. [CFDA]

30. VETERANS HOUSING—DIRECT LOANS TO DISABLED VETERANS

Authorization:	38 U.S.C. 1811
CFDA:	64.118
Agency:	Veterans Administration
FY 1986 Est.:	$9,238,000
Disabled Persons Benefiting:	30,000

This program provides loans averaging $32,000. [CFDA]

31. DEVELOPMENTAL DISABILITIES—UNIVERSITY AFFILIATED FACILITIES

Authorization:	PL 98-527
CFDA:	13.632
Agency:	Department of Health and Human Services
FY 1986 Est.:	$9,000,000
Disabled Persons Benefiting:	Information Unavailable

Some 35 demonstration and dissemination projects are funded. [CFDA]

32. BLIND VETERANS REHABILITATION CENTERS

Authorization:	38 U.S.C. 601, 3021
CFDA:	64.007
Agency:	Veterans Administration
FY 1986 Est.:	$8,205,000
Disabled Persons Benefiting:	734

This program supports VA hospital programs serving blinded veterans. [CFDA]

33. SECONDARY EDUCATION AND TRANSITIONAL SERVICES FOR HANDICAPPED YOUTH

Authorization:	PL 98-199
CFDA:	84.158
Agency:	Department of Education
FY 1986 Est.:	$6,330,000
Disabled Persons Benefiting:	Information Unavailable

This program made 34 grants in FY 1984 for projects on secondary and postsecondary education of handicapped youth. [CFDA]

34. CLIENT ASSISTANCE PROGRAM FOR HANDICAPPED INDIVIDUALS

Authorization:	29 U.S.C. 732
CFDA:	84.161
Agency:	Department of Education
FY 1986 Est.:	$6,300,000
Disabled Persons Benefiting:	Information Unavailable

This program supports State agency assistance for clients of State rehabilitation agencies. By law, the State governor selects the agency to administer the CAP program. [CFDA]

35. HANDICAPPED—REGIONAL RESOURCE CENTERS

Authorization:	20 U.S.C. 1421
CFDA:	84.028
Agency:	Department of Education
FY 1986 Est.:	$6,000,000
Disabled Persons Benefiting:	Information Unavailable

Provides grants to establish and operate resource centers assisting school districts and teachers. [CFDA]

36. POSTSECONDARY EDUCATION PROGRAMS FOR HANDICAPPED PERSONS

Authorization:	PL 98-199
CFDA:	84.078
Agency:	Department of Education
FY 1986 Est.:	$5,300,000
Disabled Persons Benefiting:	Information Unavailable

This program provides demonstration grant monies to support interpreting, reading, notetaking, tutoring, counseling and related services for postsecondary students who are handicapped. A total of 21 projects were supported in FY 1984, including four continuation grants. Priority is given to four regional programs serving deaf students. [CFDA]

37. LONGSHORE AND HARBOR WORKERS' COMPENSATION

Authorization:	36 U.S.C. 501; 42 U.S.C. 1651, 1701; 43 U.S.C. 1333; and 5 U.S.C. 8171
CFDA:	17.302
Agency:	Department of Labor
FY 1986 Est.:	$4,500,000
Disabled Persons Benefiting:	14,250

This program makes direct payments to longshore workers, harbor workers, and certain other employees to compensate for total or partial disability. About two-thirds of base pay is provided. [CFDA]

38. INNOVATIVE PROGRAMS FOR SEVERELY HANDICAPPED CHILDREN

Authorization:	20 U.S.C. 1424
CFDA:	84.086
Agency:	Department of Education
FY 1986 Est.:	$4,300,000
Disabled Persons Benefiting:	4,730

This program offers contracts to improve educational or training services for severely handicapped children and youth. In addition to the students served, some 2,000 professionals benefit from training on independent living and parental involvement. [CFDA]

39. HANDICAPPED—SPECIAL STUDIES

Authorization:	PL 98-199
CFDA:	84.159
Agency:	Department of Education
FY 1986 Est.:	$2,000,000
Disabled Persons Benefiting:	Information Unavailable

This program supports data collection and impact studies of program effectiveness in the area of education for disabled persons. [CFDA]

40. PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

Authorization:	Executive Order 11480
CFDA:	53.001
Agency:	PCEH
FY 1986 Est.:	$2,000,000
Disabled Persons Benefiting:	Information Unavailable

PCEH sponsors an Annual Meeting and selected other conferences and issues several publications, to enhance employment of disabled youths and adults. [CFDA]

41. ARCHITECTURAL AND TRANSPORTATION BARRIERS COMPLIANCE BOARD

Authorization:	42 U.S.C. 4151 et seq.
CFDA:	88.001
Agency:	ATBCB
FY 1986 Est.:	$1,930,000
Disabled Persons Benefiting:	Information Unavailable

The Board enforces the Architectural Barriers Act of 1968, issues minimum requirements for four standard-setting Federal agencies, and provides technical assistance on removal of barriers facing physically disabled persons. [CFDA]

42. PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

Authorization:	Executive Order 12110
CFDA:	13.613
Agency:	Department of Health and Human Services
FY 1986 Est.:	$800,000
Disabled Persons Benefiting:	Information Unavailable

PCMR conducts public information and advisory activities. [CFDA]

43. NATIONAL COUNCIL ON THE HANDICAPPED

Authorization:	29 U.S.C. 780–785
CFDA:	
Agency:	NCH
FY 1986 Est.:	$750,000
Disabled Persons Benefiting:	Information Unavailable

The Council advises the Congress and the President on Federal policies toward disabled persons and sets policies for the National Institute for Handicapped Research. [NCH]

44. HANDICAPPED ASSISTANCE LOANS

Authorization:	PL 97–35; small Business Act of 1953
CFDA:	59.021
Agency:	Small Business Administration
FY 1986 Est.:	-0-; FY 85 Est.: $30,000,000
Disabled Persons Benefiting:	164

The Administration proposed to eliminate the SBA in FY 1986. Loans are made to individuals or to organizations for working capital, construction, and other business expenses. Loans in FY 1984 ranged from about $500 to about $350,000; with the average being $88,900. [CFDA]

45. DEVELOPMENTAL DISABILITIES—SPECIAL PROJECTS

Authorization:	PL 98–527
CFDA:	13.631
Agency:	Department of Health and Human Services
FY 1986 Est.:	-0-; FY 85 Est.: $ 2,700,000
Disabled Persons Benefiting:	Information Unavailable

This program, which was recommended for elimination by the Administration in FY 1986, provides grants to support innovative work in integrating developmentally disabled persons into the community. About 30 projects were supported in FY 1985. [CFDA]

Notes to the Listing

1. **Sources.** Most information derives from the *Catalog of Federal Domestic Assistance—1985* (Office of Management and Budget [OMB]; Government Printing Office, 1985). In some instances, as with the number of persons participating in independent living programs or in state-operated or -supported schools, program officials in the U.S. Department of Education were consulted. In a few instances, as with the number of disabled persons benefiting from Medicare or from section 8 housing assistance, program officials were not able to provide the needed information but publications such as *Social Security Bulletin* or university researchers, notably at the Bureau of Economic Research, Rutgers University (Professors Berkowitz, David, and Worrall) were able to provide estimates.

2. **Excluded.** Not included in this priority listing are the "special institutions"—Gallaudet College, National Technical Institute for the Deaf, Helen Keller National Center, American Printing House for the Blind—each of which has funding set by the Congress and none of which is administered by an executive branch agency. These programs do not appear in the CFDA. Also excluded from this priority listing are a few programs designed to train special educators or rehabilitation personnel; the basis for exclusion is that these programs do not benefit disabled persons so much as professionals in human service fields.

3. See also: Berkowitz, Monroe. *Disability Expenditures 1970–1982.* New Brunswick, NJ: Rutgers University, 1985.

Biographies of Members of The National Council on the Handicapped

Sandra S. Parrino

Sandra S. Parrino, of Briarcliff Manor, New York, was appointed Chairperson of the National Council on the Handicapped in 1983 by President Reagan. She has been actively involved in issues concerning disabled people for many years. Her 20 year old son, Paul, has been severely physically disabled for most of his life. She is best known as a spokesperson for parents of disabled children, as a panelist, lecturer, lobbyist, and organization official.

Mrs. Parrino serves on numerous boards and councils. She has been director for the Office of the Disabled in Ossining and Briarcliff Manor, New York; she has served on the board of Westchester County Homes for the Retarded; and she has been a member of the New York State Assembly Task Force on the Disabled, which reviews pending legislation in the State of New York. Through her efforts, many local advances have been made to improve accessibility for disabled people, such as setting up transportation services and installing voting machines for disabled persons, fundraising to provide interpreter services for deaf people, and supervision of the school district's compliance with Federal regulations. Her major interest since becoming a member of the Council has been promoting independence and equality for people with disabilities.

Mrs. Parrino is also a member of the board of Parent Chain, and has served as an American representative to the United Nations and UNICEF for the International Year of Disabled Persons. She is currently the North American Vice President of Rehabilitation International, a worldwide service, information, and advisory organization.

H. Latham Breunig, Ph.D.

H. Latham Breunig, Ph.D., resides in Arlington, Virginia. He is retired from Eli Lilly and Company, Indianapolis, Indiana. At age three, Dr. Breunig had a 25 percent hearing loss, and at age seven his loss of hearing was 95 percent. He attended Wabash College, Indiana; earned his Ph.D. in Chemistry from Johns Hopkins University; and also studied at Purdue University, Indiana, in the field of Statistics and Quality Control.

Among the many organizations where Dr. Breunig has been active are the President's Committee on Employment of the Handicapped; the American Statistical Association; the Clarke School for the Deaf; and the Alexander Graham Bell Association for the Deaf, where he has served on the Board of Directors for the past twenty-four years, two of them as President. He founded Telecommunications for the Deaf in 1968, and was Chief Executive Officer until 1978. He has been active in the development of oral interpreters for deaf people.

Special awards presented to Dr. Breunig have included the President's Committee on Employment of the Handicapped Commendation by President Johnson in 1967; Sertoma International, Midwest Region,

Service to Mankind in 1968; Sagamore of the Wabash (Governor Branigin of Indiana) in 1969; and Telephone Pioneers, Honorary Member, in 1973. In 1977, Teletypewriters for the Deaf, Inc. made him the first recipient of its H. Latham Breunig Award. Dr. Breunig was honored by Wabash College in 1984 with its Alumni Award of Merit.

Robert V. Bush, C.P.O.

Robert V. Bush, Certified Prosthetist and Orthotist, resides in Albuquerque, New Mexico, and is a Clinical Associate with the New Mexico Medical School. He is presently chairperson of the University of New Mexico Medical Center Board of Trustees, and is a member of both the Heights General Hospital Board of Trustees, and the New Mexico Multiple Sclerosis Society Board of Directors. He has been active with the VA prosthetic/orthotic programs, as well as the Division of Vocational Rehabilitation. He is past chairperson of the Bernalillo County Mental Health, Mental Retardation Board of Trustees. He has also served as President of the American Orthotic/Prosthetic Association.

As a Prosthetic/Orthotic technician for Walter Reed Hospital, Mr. Bush did research on upper extremity prosthetics, particularly at Northrup Aircraft, setting up the plastic shops in five Army Amputee Centers. Later he was manager of A. J. Hosmer Corp., doing research, and was a leading manufacturer of upper extremity prosthetic components.

Justin W. Dart, Jr.

Justin W. Dart, Jr. resides in Fort Davis, Texas, and Washington, D.C. A wheelchair user since 1948, he has been active as an advocate for the rights of disabled and disadvantaged persons for more than 30 years. He has served as Chairman and as a member of the Texas Governor's Committee for Persons with Disabilities (1980–85), as Chairman of the Governor's Long Range Planning Group for Texans with Disabilities (1982–83), and as Vice Chairperson of the National Council on the Handicapped (1982–85). He continues to serve as a member of the Texas Council on Disabilities.

Mr. Dart founded Japan Tupperware (a division of Dart Industries, now Dart and Kraft) in 1963, and served as its President until 1965. From 1968 to the present, he and Mrs. Dart have operated a private independent living program; more than 70 disabled and nondisabled persons have spent from six months to four years in their home, before moving on to successful programs of education and employment.

Mr. Dart received his B.S. and M.A. degrees from the University of Houston in 1953–54, and attended the University of Texas Law School 1955–56. He has edited two books of poetry, and has authored papers on the philosophy and administration of independent living programs. He served as coordinator and lead editor of the Long Range Plan for Texans with Disabilities, and of the National Policy for Persons with Disabilities.

Joe S. Dusenbury

Joe S. Dusenbury lives in Columbia, South Carolina. He is past Chairperson of the National Council on the Handicapped. He has been with the South Carolina Vocational Rehabilitation Department since 1960, and has been Commissioner since 1976. He oversees a wide range of services necessary to rehabilitate physically and mentally handicapped individuals in the statewide network of more than one hundred offices and programs.

Mr. Dusenbury has had ten years experience as the principal of both elementary and junior high schools. While principal of a junior high school, he organized the first "ability groups" in the area, thus recognizing the special educational class for educable mentally retarded students on a secondary level.

As an active member of the National Rehabilitation Association (NRA), he has been both Program Chairperson of the Regional NRA and President of the Regional and National NRA. He has also been President of the South Carolina Vocational Education Association. He currently serves as Vice-Chairperson of the South Carolina Occupational Information Coordinating Committee and as Chairperson of the South Carolina Governor's Committee on Employment of the Handicapped.

Among his most notable awards for public service are: the Distinguished Public Service Award from the American Legion Department of South Carolina in recognition of outstanding contributions to his community, state, and nation; the National Rehabilitation Association President's Award for outstanding achievements on behalf of disabled persons; and the Mary E. Switzer Award for excellence in performance of rehabilitation leadership from the National Association of Rehabilitation Administrators. He is the only recipient of the Region IV RSA Commissioner's Award in recognition of his constant outstanding leadership in programs having a positive impact on the lives of disabled persons. In 1984 he was honored by having the new State Office Building, which houses the Vocational Rehabilitation Department, named the Joe S. Dusenbury Building in recognition of his determined efforts to improve opportunities for the state's disabled citizens.

John S. Erthein

John S. Erthein lives in Los Angeles, California, where he is currently the President of John S. Erthein, Inc., a public relations firm with offices in Los Angeles and Washington, D.C., and producer of the upcoming motion picture, *Monimbo,* from the book of the same title by Robert Moss and Amaud de Borchgrave. Mr. Erthein previously served as Vice President of Marketing for a major specialty greeting card publisher, Nu-Art, Inc., in Chicago, Illinois. Earlier, as a management consultant, Mr. Erthein successfully completed marketing assignments for numerous major clients in a variety of fields.

He is on the Board of Directors for the American Paralysis Association, an organization that has as its primary objective funding research for the nation's 500,000 spinal cord injured individuals and their families.

Mr. Erthein, a graduate in Marketing from Columbia University, served as an officer in the United States Coast Guard, and was Security Officer and Public Information Officer for his unit in New York.

He was Assistant for Finance for Citizens for the Republic, when Ronald Reagan chaired that organization. Subsequently, he assisted in setting up the fundraising organization for the 1980 Reagan Presidential campaign.

He is currently producing a number of programs for release on video cassette.

R. Budd Gould

R. Budd Gould was born in Pasadena, California and lives in Missoula, Montana. He has been blind since age 33. He attended the University of Montana in Missoula in the area of Business Administration.

Mr. Gould was elected to the Montana State House of Representatives in 1974 and is currently serving his fifth term. In 1975, 1977, 1979, and 1981, he served on the Public Health Committee and was chairman of that committee in 1981.

He has been active in human service and rehabilitative endeavors. Mr. Gould serves on the Montana State Library Advisory Council, to which he was first appointed in 1972. He was Chairman for Region Five of Montana on the White House Conference on Handicapped Individuals, and served on the Rehabilitation Services Advisory Council in 1976, the Visual Services Advisory Council in 1977, and on the Board of Directors of the Western Montana Radio Reading Service in 1979.

Mr. Gould has received numerous awards for his outstanding service, including the Man of the Year Award in 1977 from the Montana Association of the Blind.

Hunt Hamill

Hunt Hamill lives in Winnetka, Illinois. From 1975 to 1983 he served as President of the Rehabilitation Institute of Chicago, affiliated with the McGraw Medical Center, Northwestern University. From 1968 to 1975, subsequent to his retirement as President of the National Sugar Refining Company (Jack Frost), he was President and Director of the Brain Research Foundation, an affiliate of the University of Chicago. He has had extensive experience in highly responsible positions in business and technical fields, serving on Boards of Directors of several technologically-oriented corporations.

As Chief Executive Officer of the Rehabilitation Institute of Chicago, a comprehensive medically-oriented center which has aided disabled persons in employment, accessibility, transportation, housing issues, public education programs, etc., he was influential in changing community attitudes and increasing the acceptance of disabled individuals.

Mr. Hamill's efforts through the Institute have had national impact on the lives of thousands of people with disabilities. He served as Chairperson of the Chicago Hospital Council in FY 1982–1983.

Marian North Koonce

Marian North Koonce of Santa Barbara, California, is the mother of six children. Two are physically handicapped from birth and a third contracted Multiple Sclerosis as a young adult. Along with the great amount of time and attention she gives to her family, she has held many administrative and leadership positions in business, most recently as Chairman of the Board of a Santa Barbara independent bank.

She is involved in numerous local and national organizations. She was Chairman of the Santa Barbara County Reagan-Bush '84 Committee. She has served as delegate to the Republican National Conventions of 1976, 1980 and 1984.

From 1980 to 1981, Mrs. Koonce was Vice-President of Recording for the Blind Auxiliary. She serves on the Board of the Santa Barbara Symphony Association; the Las Positas Park Board; the Board of Trustees of the University of California, Santa Barbara; and is Chairman of the Channel Islands Chapter of the National Multiple Sclerosis Society.

Nanette Fabray MacDougall

Nanette Fabray MacDougall, a resident of Pacific Palisades, California, is a renowned actress who developed a progressive hearing disability. Following four operations, the difficulty, which threatened her with total deafness, was cured. She has continued to be active in organizations benefiting hearing-impaired and other disabled persons.

Mrs. MacDougall was Regional Chairperson of the National Easter Seal Society for Crippled Children, and the National Mental Health Association. She is past Chairperson of the National Advisory Committee for Education of the Deaf. She currently serves on the Board of the National Captioning Institute, the Better Hearing Institute in Washington, D.C., as well as the House Ear Institute and the Museum of Science and Industry.

Among the many awards she has received are the President's Distinguished Service Award (1971) and the Eleanor Roosevelt Humanitarian Award (1964). Mrs. MacDougall and Helen Keller are the only two women ever to have received the annual Public Service Award of the American Academy of Ophthalmology and Otolaryngology. She has two honorary doctoral degrees, one from Gallaudet College and one from Western Maryland College. She was one of the original members of the National Council on the Handicapped, and was reappointed by President Reagan.

Michael Marge, Ed.D.

Michael Marge, Ed.D., of Syracuse, New York, has been Professor of Special Education and Rehabilitation (Communicative Disorders) and Professor of Child and Family Studies, Syracuse University, since 1974. He was Dean of the College for Human Development from 1974–1979. He has been active in special education and rehabilitation for more than thirty years. He began his career as Director of the Upstate New York Speech and Hearing Therapy Project for the Easter Seal Society. He developed the Glens Falls, NY Cerebral Palsy Clinic and the Northeastern New York Cleft Palate Center; was Director of Speech Therapy Services for the Mount Carmel Guild Programs for the Handicapped, Newark, NJ, which provided services for more than 200 elementary and secondary schools; and he founded and served as Co-Chairman of the Department of Communicative Disorders at Seton Hall University from 1960–1964.

In 1964 he served at the U.S. Office for Education as Program Coordinator for Speech and Hearing Services in the Division of Handicapped Children and Youth, later becoming Director of Program Planning and Evaluation for the Bureau of Education for the Handicapped. He was Deputy Commissioner of Education for Planning Research and Evaluation (1969–1971), and Deputy Director of the Bureau of International Studies (1971–1974).

He is a member of numerous professional organizations, serving as an officer and chairperson of selected committees. Currently, he is Chairman of the ASHA Committee on Prevention of Communicative Disorders and the Central New York Committee on Disability Prevention. In 1980 he received a Mary E. Switzer Fellowship Award for his contributions to disability prevention. He is the author of a textbook on language disability in children and more than thirty publications on communicative disorders, special education and rehabilitation.

Jeremiah Milbank, Jr.

Jeremiah Milbank, Jr. of Greenwich, Connecticut, graduated from Yale University in 1942, and Harvard Business School in 1948, after which he worked in the private investment business in New York.

Mr. Milbank has held a leadership position in both community and national organizations, including President of the J. M. Foundation, Boys Clubs of America, and the International Center for the Disabled. He has been Chairman of the Republican National Finance Committee, 1969–72 and 1975–77; he is on the Board of Governors of the Ronald Reagan Presidential Foundation; and is a Trustee of the Taft Institute for Two Party Government. A recipient of the President's Award for Voluntary Action, 1983, he also holds three honorary degrees.

Roxanne S. Vierra

Roxanne S. Vierra of Littleton, Colorado has been actively involved in business as well as in community and political affairs. Her son, Steven, had brain damage from birth. His handicap gave her insight into the needs of mentally retarded individuals. This insight caused her to develop Retarded Unlimited, Inc., an organization designed to establish business ventures owned and operated by mentally retarded persons. Her objective is to make mentally retarded people more self-sufficient and less dependent on government funds. Steven is an example of what a mentally retarded individual can do: He lives in his own townhouse, works as a courtesy clerk at a grocery store and is relatively independent.

Mrs. Vierra serves as an officer of the Children's Diabetes Foundation, which is dedicated to research in finding a permanent cure for children's diabetes. She is on the Board of Directors of the American Lung Association, and is President of the Board of Childhelp USA, a national organization to prevent child abuse. She has campaigned and organized numerous activities in national elections including fundraising in President Reagan's campaign. In the business world, Mrs. Vierra has been a Broker Associate for the Devonshire Company selling residential property for the past six years.

Henry Viscardi, Jr.

Henry Viscardi, Jr., LLD (Hon.) of Long Island, New York is highly respected in the fields of rehabilitation and education. Born without legs and confined to a public ward in a hospital for the first seven years of his life, Dr. Viscardi has devoted his life to insuring that severely disabled individuals have the opportunity to achieve their fullest potential.

Dr. Viscardi has been an adviser to Presidents and has been awarded over a dozen honorary degrees including doctorates in law, science, humane letters and literature. He has written numerous books, and the National Rehabilitation Association presented him with its highest honor, The President's Award Medal. His international activities include missions to India, Egypt, the Scandinavian countries, Australia and Western Europe.

In 1952 Dr. Viscardi founded the internationally famed Human Resources Center in Albertson, New York. Through this Center, he has shown that disabled people can be fully integrated into every phase of American life from infant education to professional accomplishments. Someone has said, "Standing on artificial limbs, he is a giant among the great Americans of our time."

Alvis Kent Waldrep, Jr.

Alvis Kent Waldrep, Jr. of Plano, Texas, is the President and Chief Executive Officer of the Kent Waldrep National Paralysis Foundation, a non-profit organization dedicated to finding a treatment and cure for paralysis caused by spinal cord injury. He is responsible for all phases of daily operations which include fundraising, budgeting and public awareness through its national office in Dallas. From September 1982 to June 1985, Mr. Waldrep was President of the American Paralysis Association.

From June 1979 to December 1981, Mr. Waldrep founded and served as Chief Executive Officer of the Kent Waldrep International Spinal Cord Research Foundation, Inc., a non-profit organization which became the American Paralysis Association. He was responsible for planning and implementing all programs designed to meet the objectives and goals of the Foundation.

Mr. Waldrep served as Assistant Sports Information Director for Texas Christian University from April 1977 to June 1979. There, he assisted the Sports Information Director with all sports promotion programs, including media communication, brochure preparation, compilation of statistics and advertising sales. This followed on three years of intensive physical therapy following paralysis caused by a cervical spinal cord injury from football in 1974 which left him a quadriplegic with paralysis from the neck down.

He is a member of several community and professional groups including the Board of the Dallas Rehabilitation Institute and The National Society for Fundraising Executives. He has been the recipient of many awards honoring him for his achievements in the area of disability. Mr. Waldrep was selected by the United States Jaycees as one of the ten outstanding young men in America for 1985.

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